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ABSTRACT

Provided are standards for agencies and hospitals serving developmentally disabled persons with emphasis on planning and implementing individual programs. The introduction provides information on the establishment of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons and the Joint Commission on Accreditation of Hospitals, development and format of the standards, and the accreditation process. Definitions, principles, and a list of numbered standards are given for the following section titles: "Individual Program Planning and Implementation", "Alternative Living Arrangements", "Achieving and Protecting Rights", "Individual Program Support", "Safety and Sanitation", "Research and Research Utilization", and "The Agency in the Service Delivery System". Appended are indices to the standards, accreditation policies and procedures, a list of organizations involved in development of the standards, and a listing of councilors of the accreditation council. A glossary of 54 terms (such as a "adaptive behavior" and "normalization") is also included. (DB)

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Standards for Services for Developmentally Disabled Individuals

A revision and merger of the
Standards for Community Agencies and
Standards for Residential Facilities

The development of these standards was supported,
in part, by a grant from the
Developmental Disabilities Office,
U.S. Department of Health, Education, and Welfare.

Adopted September 20, 1977

**Accreditation Council
for Services for
Mentally Retarded and Other
Developmentally Disabled Persons**

Joint Commission
on Accreditation of Hospitals

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Introduction

The standards contained in this document were developed by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MRDD). The Council is a consortium of professional, service-provider, and consumer-advocate organizations working to improve services for developmentally disabled individuals by:

- developing valid standards for services of high quality;
- providing instruction in the meaning and implementation of the standards and encouraging their use;
- developing reliable means of assessing compliance with the standards;
- assessing, on request, the compliance of agencies with the standards; and
- recommending the award of accreditation by the Joint Commission on Accreditation of Hospitals (JCAH) to agencies found to be in substantial compliance with the standards.

Established in 1969 as the Accreditation Council for Facilities for the Mentally Retarded (AC/FMR), the Council's name was changed in 1976 to reflect its concern for all developmental disabilities. The Council is organized as a component of JCAH.

Establishment of the Council

Although standards developed by AC/MRDD were the first to be published for use in a formal accreditation program for agencies serving developmentally disabled individuals, the development of such standards began in 1952 when the American Association on Mental Deficiency (AAMD) published the report of a special committee on standards for institutions. Seven years later, AAMD, supported by a grant from the National Institute of Mental Health, undertook a major standards-development project, which culminated in 1964 with the publication of *Standards for State Residential Institutions for the Mentally Retarded.* These standards were presented as minimal, as generally attainable within five to ten years, and as a basis for evaluation and accreditation activities. Concurrent with the publication of the *Standards,* the AAMD established a committee to continue reviewing and revising the *Standards* and to encourage their implementation by 1) evaluating, on request, the compliance of institutions with them and 2) planning for the establishment of a formal accreditation program. During 1966-69, grants from the Mental Retardation Branch of the U.S. Public Health Service (subsequently renamed the Division of Mental Retardation in the Social and Rehabilitation Service, U.S. Department of Health, Education, and Welfare) enabled the evaluation of 134 state institutions for mentally retarded individuals. These institutions comprised three-quarters of all such institutions in this country and housed ninety percent of the residents of public facilities.

During this period, other organizations, notably the American Psychiatric Association and the National Association for Retarded Children (now the National Association for Retarded Citizens), also evinced interest in the development of standards for residential facilities for mentally retarded individuals. Fortunately, those persons trying to establish a formal accreditation program recognized the desirability of delegating responsibility for standards-setting and survey operations to a single agency that would represent organizations concerned with services for mentally retarded individuals. Accordingly, AAMD instigated the formation of the National Planning Committee on Accreditation of Residential Centers for the Retarded in 1966. The Committee was composed of representatives from AAMD, the American Medical Association, the American Psychiatric Association, the Council for Exceptional Children, the National Association for Retarded Children, and the United Cerebral Palsy Associations. The inclusion of representatives of both consumer-advocate and professional groups on the Committee was especially significant.

With support from the Division of Mental Retardation, the National Planning Committee developed the structure for an accrediting agency, which was established in 1969 as what is now known as the AC/MRDD within the Joint Commission on Accreditation of Hospitals. The original membership of the Council included all of the National Planning Committee's member organizations except for the American Medical Association, which is a corporate member of the Joint Commission. In 1973, the American Academy of Pediatrics, American Nurses' Association, American Psychological Association, and National Association of Private Residential Facilities for the Mentally Retarded became members of the AC/MRDD, while the Council for Exceptional Children withdrew. The Epilepsy Foundation of America, National Association of Social Workers, and National Society for Autistic Children became members in 1978. Each member organization makes an annual financial contribution to the work of the Council and appoints two Councillors. These Councillors constitute the governing body of the AC/MRDD. HEW's Developmental Disabilities Office—the successor to its Division of Mental Retardation—has given continual support to the Council's programs.

The Joint Commission

The Joint Commission on Accreditation of Hospitals was established in 1951 by the American College of Physicians, American College of Surgeons, American Hospital Association, and American Medical Association to carry on the hospital accreditation program founded by the American College of Surgeons in 1918. The Canadian Medical Association was a member of the JCAH until 1959, when the Canadian Council on Hospital Accreditation initiated its own program. Until 1965, the Joint Commission's activities were generally limited to hospitals. However, while its standards and survey procedures were written for general hospitals, other types of institutions that lacked accreditation programs in their own areas occasionally sought JCAH accreditation. These included institutions for the mentally retarded, some of which contained hospital or infirmary units.

The demand for accreditation from facilities other than hospitals encouraged the Joint Commission to consider expansion of the accreditation programs under its aegis. The Joint Commission began to offer accreditation to long term care facilities in 1965, with the concurrence and participation of organizations previously active in the field. During the next year, the newly-formed Commission on Accreditation of Rehabilitation Facilities contracted with the Joint Commission for the operation of its program. Finally, in 1969, the Joint Commission authorized the establishment of various accreditation councils in response to requests from organizations that perceived a need for national accreditation of facilities or services in their areas of concern.

The establishment in 1969 of what is now AC/MRDD was followed by the establishment of the Accreditation Council for Psychiatric Facilities in 1970. The Accreditation Council for Long Term Care Facilities was established in 1971 to continue and to expand the JCAH accreditation program that had been serving such facilities since 1965. The Accreditation Council for Ambulatory Health Care was founded in 1975. The Commission on Accreditation of Rehabilitation Facilities began to operate independently of JCAH in 1972.

Voluntary Accreditation

Accreditation differs from but complements licensing, which is a governmental activity that usually focuses upon the enforcement of minimum standards for health and safety. An agency often must be licensed in order to offer services to the public. However, an agency may elect to participate in voluntary accreditation and thereby conform to standards of service more demanding than minimum licensing requirements. As a voluntary activity, accreditation is concerned with optimal achievable rather than minimal quality, and with evaluation and education rather than inspection and enforcement. A voluntary accreditation program provides for continuing and objective evaluation of services through a mechanism that minimizes domination and interference. It also provides freedom to experiment and innovate on the part of the service agency, and to improve standards and refine methods of evaluation on the part of the accrediting body.

As an educational and evaluative process, AC/MRDD accreditation offers several significant advantages over other systems. Its standards are developed with the participation of a large and diverse assemblage of service providers and consumers, and thus do not merely reflect the opinions of one particular group. The standards are comprehensive and detailed, rather than limited to only certain aspects of an agency's services, and they are useful for self-appraisal and self-education in an agency's efforts to improve its services. Since the on-site survey of an agency's compliance with the standards is preceded by the agency's self-assessment of compliance, the total survey process combines the benefits of both internal and external evaluations. Whether or not it results in accreditation, a survey provides an objective evaluation that helps to identify strengths and weaknesses, to furnish teaching/learning management tools, to secure needed action, and to demonstrate the agency's desire to provide services of high quality.

The ultimate goal of the accreditation process is to achieve and maintain accreditation, which signifies that an agency has attained substantial compliance with applicable standards. By so identifying agencies that have met nationally recognized standards, accreditation helps to protect the recipient of services. An agency must regularly and systematically evaluate its performance against accepted standards in order to assure continuing services of high quality. By providing for the documentation of such evaluation, the accreditation process also generates evidence of the agency's accountability to the persons and organizations that are served by it and that support it.

Development of the Council's Standards for Residential Facilities and Standards for Community Agencies

Although the Accreditation Council is charged with the task of developing standards, it obviously cannot possess the range of expertise required to develop standards for every kind of service needed by developmentally disabled individuals. Consequently, it is the Council's role 1) to procure the assistance of numerous persons and groups for the development of appropriate program area standards, and 2) to coordinate these developmental activities so that an integrated set of standards for the assessment of overall program adequacy may be assembled. The Council performs its role by asking organizations concerned with services for developmentally disabled individuals to participate in the development of standards, and by occasionally establishing advisory committees whose members possess appropriate professional and/or consumer knowledge and interests. For the fundamental and crucial activity of setting standards, the Council not only welcomes, but actively seeks to facilitate, the involvement and participation of all relevant and interested parties.

More than 600 professional and consumer representatives participated in the development of the Council's *Standards for Residential Facilities for the Mentally Retarded*, published in 1971, and its *Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities*, published in 1973. The *Standards for Residential Facilities* were drafted by 20 committees representing all disciplines and interests that play an essential role in the provision of fully adequate services. Recognizing that the problems associated with mental retardation and other developmental disabilities do not fall within the purview of any single discipline, and that the alleviation of these problems requires knowledge and skills associated with a variety of professions, an interdisciplinary philosophy was implemented in both the composition and operation of the committees. Consequently, while each committee was given primary responsibility for drafting standards geared to a specific area of service, no part of the *Standards* was the exclusive concern of any particular discipline, and the draft standards as a whole were subject to review by all committees. The membership of the committees reflected the broadest possible assortment of viewpoints, program approaches, administrative levels, and service settings (public and private, residential and nonresidential, direct and indirect), and included representatives from 47 national organizations concerned with services addressed by the standards. The draft standards developed by the advisory committees were periodically reviewed by the Council's own Standards Committee, and the final compilation of all drafts was critiqued by three additional committees representing service consumers, administrators of state programs, and administrators of public and private facilities.

The *Standards for Community Agencies* were developed by a 26-member advisory committee composed of parents, practitioners, program directors, state agency and university personnel, and representatives of national organizations concerned with services for developmentally disabled individuals. The committee was able to draw upon the Council's past experience in developing the standards for residential facilities and was assisted by 60 expert consultants and reviewers representing various service areas. In addition, the final draft of the standards was reviewed by more than 40 community agencies and nearly 400 representatives of national, regional, and state professional and consumer organizations.

Both the *Standards for Residential Facilities* and the *Standards for Community Agencies* reflected the following basic assumptions:

1. The developmentally disabled individual has the same fundamental rights as other persons, plus the right to receive adequate treatment and habilitation.
2. The most useful way to view mental retardation and other developmental disabilities is within the context of a developmental model that acknowledges each individual's capacity for learning, growing, and developing, regardless of how severely disabled he or she may be.
3. Services must be provided to meet the developmental needs of the disabled individual throughout his or her life span, so as to maximize the individual's human qualities, increase the complexity of the individual's behavior, and enhance the individual's ability to cope with his or her environment.
4. Services must be provided in accordance with the principle of normalization, defined as the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible.
5. Standards for services for developmentally disabled individuals should emphasize the provision of adequate programming for each individual, using a thoroughly interdisciplinary approach.
6. Each standard should be necessary or desirable for providing services that are fully adequate, as defined by the best available knowledge and practice.
7. Standards should reflect emphasis on a continuum of development rather than on categories of service. They should be applicable to large and small, public and private agencies and should not mandate particular administrative or organizational arrangements unless such arrangements have been demonstrated to be essential for the provision of adequate service.
8. Standards should provide guidelines for the development of services, as well as methods for assessing their adequacy.
9. Standards should be stated clearly and, whenever possible, in behavioral terms, so that compliance with them can be reliably assessed. When appropriate, standards should be expressed in terms of applicability to an individual, so that their applicability to an agency may be determined by their applicability to the individuals it serves.

Merger of the Standards into Standards for Services for Developmentally Disabled Individuals

The Accreditation Council's objective is to promote the delivery of comprehensive and coordinated services within a service delivery system that meets all the needs of every developmentally disabled individual by utilizing whatever settings are available and appropriate, and generic resources whenever possible. Accordingly, while various considerations made it necessary initially to publish separate standards for residential facilities and community agencies, the former were designed for application to all residential programs (ranging from group homes to institutions) and the latter for all nonresidential services. The Council has refrained from publishing standards for particular categories of services, or for particular settings in which services may be provided (such as schools, activity centers, workshops, group homes, or residential centers), in the belief that such standards would encourage the fragmentation, rather than integration, of services. The merger of the residential facility and community agency standards into a single set of standards was planned when the community agency standards were published and thus represents the appropriate fulfillment of the Council's objective. In addition, the merger makes it possible to implement a single accreditation program for all services for developmentally disabled individuals, using a single set of compliance assessment procedures and a single set of accreditation requirements.

In preparing to merge the standards, the Council undertook a comprehensive review and revision of the *Standards for Community Agencies,* based on three years of experience in applying the standards and assessing compliance with them. The revised standards were then collated with the *Standards for Residential Facilities,* which had been revised annually on the basis of field experience. Standards remaining after the elimination of redundancies were assigned to topics that represented the reasons for requiring compliance with them. Since a standard may relate to two or more topics, some assignments were necessarily arbitrary. A similar procedure had been followed in organizing the *Standards for Community Agencies* and in categorizing selected standards in the *Standards for Residential Facilities* under the "Topical Requirements for Accreditation."

More than 1,000 copies of the first draft of the standards were distributed for review and comment. Copies were issued to all agencies and facilities previously surveyed under the community agency and residential facility standards, to national organizations concerned with services for developmentally disabled individuals, and to state agencies and organizations involved in the provision of such services. The Council hosted two, three-day meetings in order to obtain recommendations for changes in the draft that were submitted by representatives of 34 national organizations concerned with services for developmentally disabled persons. Written comments and recommendations were received from 59 other sources, including facilities and agencies that had been surveyed, and state mental retardation and developmental disabilities agencies and organizations. All comments and recommendations were reviewed by the Council's Standards Committee during its preparation of the final draft of the *Standards for Services for Developmentally Disabled Individuals,* which was adopted by the Council on September 20, 1977, and ratified by the Board of Commissioners of the Joint Commission on October 27, 1977.

Format of the Merged Standards

The organization of the *Standards for Services for Developmentally Disabled Individuals* reflects the conviction that the activities of agencies serving individuals with developmental disabilities must focus upon planning and implementing individual programs in accordance with developmental principles and the principle of normalization, recognizing and providing for the rights of developmentally disabled individuals and their families. All other agency functions must be supportive of these activities. Residential services are viewed as part of the total continuum of services that should be provided by a service delivery system. The merged standards reflect attempts to express the former residential facility and community agency standards in similar terminology. The terms "mental retardation" and "mental retardation and other developmental disabilities" have been replaced by "developmental disabilities." The term "agency" is used throughout to refer to the organizational entity providing services, including residential services. The term "individual" is employed to refer to the recipient of services, replacing the term "client," as used in the community agency standards. Where the intent is to refer specifically to the recipient of residential services, the term "resident" is used. While an effort has been made to reduce redundancies within and between sections of the standards, some redundancy remains for the sake of emphasis or coherence. An effort has also been made to state definitions, principles, and standards clearly and completely in order to eliminate the need for supplementary explanations and interpretations.

Applicability of the Standards

The standards are designed for application to all agencies serving developmentally disabled individuals. They are, however, applied selectively, depending upon their pertinence to a given agency's operation.

The standards' pertinence to an agency applying for an accreditation survey is determined in accordance with the principles that should govern a service delivery system stated in Section 7. As indicated therein, service delivery systems that promote normalization exhibit certain indispensible characteristics, which should be reflected in the operation of every agency:

1. Each agency must be able to respond to any individual appeal by initiating direct service itself, by referring to an appropriate source and systematically following-up to see that the problem is resolved, or by demonstrating affirmative action to facilitate the availability and accessibility of needed services.
2. Every agency must coordinate its programs with other resources and be, or seek to become, part of a service delivery system that provides all services necessary to meet the needs of disabled individuals within the community that it serves.
3. Because the service delivery system must focus upon the individual in need, all services to an individual must be delivered in accordance with an individual program plan that specifies both the individual's identified needs and the activities designed to meet them.
4. The system for assuring continual support of individual program planning and implementation must include activities involving case finding, entry into the service system, follow-through, and the achievement and protection of rights.
5. To assure effective services, each agency must have built-in mechanisms for comparing the results of its services with its goals, and for effecting necessary changes promptly and efficiently.

A statement appearing before each group of standards in this document indicates whether the standards following it pertain to all agencies surveyed or only to those that do or do not provide the specialized services indicated. Among a group of standards that do pertain to a given agency, one or more standards may be inapplicable to the agency's particular operation. *In general, applicability is determined with reference to the needs of* *individuals served by the agency: a standard may be inapplicable to an agency if the service or activity it requires is not necessary to meet the needs of the individuals served.* In addition, compliance with certain standards may be achieved if the activities they require are provided by other agencies within the surveyed agency's service delivery system. An index of standards pertaining to agencies applying for survey is provided in Table A on page 142 of Appendix A.

Assistance in Understanding and Implementing the Standards

Recognizing its obligation to provide instruction in both the meaning of the standards and the methods for implementing them, the Council offers Accreditation Workshops designed to aid funding agencies, service providers, and consumer representatives and advocates in using the standards and accreditation process to improve services for developmentally disabled individuals. Workshops are conducted by the Council's surveyors and may be sponsored by consumer groups, governmental agencies, voluntary organizations, service agencies, regional organizations, or virtually any other group or person interested in improving such services. Three basic types of workshops are offered, based on the participants' previously acquired knowledge and their current or eventual degree of involvement in the accreditation process:

- A one-day workshop provides an introduction to the accreditation process for persons who may have no prior knowledge of the standards. Through lectures, discussion, and the use of audiovisual materials, participants are able to gain a basic understanding of the purpose and structure of the Accreditation Council; the philosophy and benefits of the accreditation process as a mechanism for program evaluation and inservice education; the steps in the accreditation process; the requirements for accreditation; and the major concepts, organization, and applicability of the standards.
- A two-day workshop provides an in-depth consideration of the standards for persons who have had some experience in implementing them. The workshop prepares participants to implement the accreditation process in their own agencies, including conducting a self-survey of compliance with applicable standards. The workshop may include simulation exercises in conducting a self-survey and in individual program planning.
- An on-site workshop is intended for agency staff members who are actively engaged in implementing the standards. It is conducted at the agency in order to assess staff members' understanding of the standards as demonstrated by their efforts to implement them. The workshop addresses an agency's specific questions concerning the interpretation and implementation of the standards within the agency's own particular setting. The length of the workshop is determined by the agency according to the guidelines for such workshops contained in Appendix B: "Accreditation Policies and Procedures."

In addition to these three basic types, special workshops may be arranged to cover particular topics, such as concepts and requirements in various sections of the standards. A more detailed description of the entire workshop program may be obtained from the Council.

Survey and Accreditation of an Agency under the Standards

Any agency may use the standards contained in this document as a guide for providing services and as a means of assessing the adequacy of those services. An agency, however, will derive maximum benefit from an assessment of its services if its self-survey is followed by an on-site survey conducted by the Council's surveyors. These professionals possess extensive experience in the provision of services for developmentally disabled individuals and are especially skilled in assessing compliance with the standards.

An agency is eligible for survey by the Council if it:

1. is an organization that provides services to—though not necessarily exclusively to—developmentally disabled individuals or their families;
2. provides services to individuals as part of a process of developing, implementing, and periodically reevaluating an individual program plan for each individual served;
3. is, or is seeking to become, part of a service delivery system offering services that meet the needs of all developmentally disabled individuals within the community that it serves;
4. operates without limitation by reason of race, color, or national origin;
5. operates in accordance with clearly defined administrative responsibility;
6. possesses a current license to operate, if such is required by the state in which it is located; and
7. has been in operation under the same ownership or control for at least one year, so that there is a record of performance that can be evaluated.

A separate, identifiable unit or component of a larger agency having a single governing body or policy-making authority (such as a mental retardation unit in a mental health institution or community mental health center) may be eligible for survey under these criteria. However, if an agency provides services in more than one category, then it is required by Joint Commission policy to seek accreditation in all categories of service for which the Joint Commission grants accreditation.

An agency may be eligible for survey regardless of whether or not it is eligible for accreditation, and an agency that is ineligible for accreditation may nevertheless receive the educational and consultative benefits that constitute the major advantages of an accreditation survey.

In order to be surveyed, an agency must be willing to participate voluntarily in both the self-evaluation process and the on-site survey. It must also agree to provide all information requested by the Council and pay all required fees. The cost of a survey depends upon the size of the agency and the complexity of its programs, as described in its completed Application for Survey. An eligible agency may obtain an application by writing to the Council.

The Council's survey procedures are designed to facilitate the reliable assessment of an agency's compliance with the standards contained in this document. This assessment places particular emphasis upon the adequacy of the programming received by, and the services delivered to, each individual served by the agency, and seeks to determine whether or not these services are being delivered in accordance with each individual's developmental needs.

Each agency that seeks accreditation must conduct a self-survey and report to the Council its self-assessment of compliance with those standards that are applicable to it. During the subsequent on-site survey, the Council's surveyors conduct a "program audit" of a sample of individuals representing various ages and disability levels. This audit is designed to assess the agency's compliance with those standards most directly related to the delivery of adequate services. The surveyor's assessments are based upon observation of, and discussion with, each individual included in the sample; discussions with direct-contact staff and other staff members responsible for implementing the individual's program; discussions with the individual's family, when appropriate; and a review of the individual's record. The Council believes that such an assessment of the processes and outcomes of services—rather than of the agency's physical and organizational structure—facilitates a more meaningful evaluation of the agency's programs. At the conclusion of the survey, the surveyors review their findings with the agency's staff and compare them to the agency's self-assessment of its compliance with the standards.

Accreditation does not require full compliance with every standard applicable to an agency. For accreditation purposes, those standards that the Council considers most important for the provision of adequate services are designated as Category A standards. An agency is ineligible for accreditation if it is found to be in less than full compliance with more than a stated percentage of the Category A standards that are applicable to it. The maximum percentage of applicable Category A standards with which accreditable agencies may be found to be in less than full compliance is determined by the Council and is the same for all agencies. Standards assigned to Category A at the time of this document's publication are identified by an asterisk (*) appearing after the standard number. *Since the list of Category A standards is periodically revised, readers are cautioned that the list contained in this document was current only at the time of publication.* An up-to-date list of Category A standards is always available from the Council.

To become accredited, an agency that is eligible for accreditation under the criteria stated above must meet the requirements for accreditation outlined on page xix of this document.

The Council's accreditation decision is based on a careful assessment of survey results and consideration of the agency's compliance with those standards with which it was found to be in less than full compliance. Each agency surveyed is provided with a written report detailing recommendations for improving its services and achieving compliance with the standards. The reasons for a decision of nonaccreditation or less than two-year accreditation are specified in each case. In the event of a nonaccreditation decision, appeal procedures provide for the full exercise of an agency's right to a fair hearing. A formal statement of the Council's accreditation policies and procedures may be found in Appendix B. The sequence of events in the accreditation survey process is summarized in Table 1 on the next page; a fuller explanation of survey procedures is contained in the *Survey Questionnaire for use with the Standards.*

Table 1. Sequence of events in accreditation survey process

AC/MRDD ACTIVITIES	AGENCY ACTIVITIES
	Secure *Standards*
	Become familiar with *Standards*, including Definitions, Principles, Glossary, and Appendices
	Orient and involve staff
	Schedule Accreditation Workshop(s), if desired
	Organize for self-survey: allocate responsibilities establish accountability system
	Secure and complete Application for Survey; submit with deposit
Process Application	
Send *Survey Questionnaire* and other self-survey materials	
	Complete self-survey and submit materials within 2 months of receipt
Review materials submitted	
Schedule on-site survey	
	Organize for on-site survey
	Schedule Public Information Interview, in consultation with surveyors
	Organize materials required for survey
	Select half of program audit sample
	Provide space and facilitating materials (calendars, maps, etc.) for surveyors
Provide initial briefing of staff	Provide initial briefing of surveyors
Schedule Summation Conference, in consultation with agency's chief executive officer	
Select program audit samples	
Review records and other documents	
Conduct interviews and observations	
Conduct Public Information Interview	
Conduct Summation Conference	
Surveyor writes Survey Report	
Council reviews Report and makes accreditation decision	
Board of Commissioners ratifies Council's decision	
Send Survey Report and decision to agency's chief executive officer and chairman of its governing body; inform agency of procedure for appealing nonaccreditation decision	
	If accredited, inform Council of changes in agency, as required
	Keep abreast of changes in standards and accreditation requirements
Schedule resurvey, in accordance with applicable policies; send Application to agency (unannounced resurvey may be conducted of accredited agency)	
	May have option of filing Progress Report or new *Survey Questionnaire*, in accordance with applicable policy

Conclusion

The *Standards for Services for Developmentally Disabled Individuals* represents the achievement of government agencies, professional organizations, practitioners in the field, and consumer representatives and advocates working together in the interest of improving services for individuals with developmental disabilities. The standards are offered to provide guidance for agency administrators and staff members in upgrading programs; to encourage the continual self-appraisal of programs; to inform members of the various professions that provide services to developmentally disabled individuals; to assist agencies in planning and developing systems of community services; to provide concrete information for legislators, consumers, and the general public; to assist consumers and consumer representatives in evaluating and monitoring services and in initiating changes when necessary; and to serve as a basis for the evaluation and accreditation of agencies. Like the previous *Standards for Residential Facilities* and *Standards for Community Agencies*, these standards will be subject to continual review and revision so that they may reflect the best, most up-to-date knowledge and practice in the field while remaining clear, comprehensive, and challenging. All individuals and organizations concerned with services for developmentally disabled individuals are encouraged to become and remain informed of the Council's standards and procedures and to advise the Council whenever changes appear to be desirable.

The Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons is dedicated to the development and implementation of standards and survey procedures that assure the delivery of services of high quality. The Council believes accreditation must attest to the demonstrated delivery of such services, and that it must be an ongoing process, continually encouraging agencies to evaluate and improve their services. On the basis of its experience to date, the Council remains confident that its accreditation process can help to improve services for individuals with developmental disabilities.

Kenneth G. Crosby, Ed.D.
Program Director
AC/MRDD

Fundamental Principles of the Standards and Requirements for Accreditation

The primary mission of each agency serving developmentally disabled individuals must be to provide and promote services that enhance the development of such individuals and maximize their achievement of self-determination and autonomy. Programs for individuals with developmental disabilities must be:

- interdisciplinary in their approach to identifying the needs of the individual and devising ways to meet them,
- based on developmental principles, and
- provided within an environment that is normalized and normalizing.

Services for each individual must be provided as part of a process of developing, implementing, and periodically reevaluating an individual program plan. The individual program plan must:

- be based on a relevant assessment of the individual's needs;
- reflect the participation of the individual and, as appropriate, the individual's family;
- provide for the coordination of the individual's total program; and
- incorporate a continuous and self-correcting process for reviewing the individual's progress and revising the plan and program accordingly.

Services must be provided within a safe and sanitary environment in accordance with policies and procedures that reflect effective administrative practices and that recognize and protect the rights of individuals and their families. Each agency must be, or seek to become, part of a service delivery system that uses generic services whenever possible and specialized services when necessary to meet the identified needs of all developmentally disabled individuals within the community that it serves.

As stated on page xvi, an agency is ineligible for accreditation if it is found to be in less than full compliance with more than a stated percentage of the Category A standards that are applicable to it. To become accredited, an eligible agency must demonstrate that its activities conform to the fundamental principles stated above.

Use of the Standards Document

In addition to making the *Standards for Services for Developmentally Disabled Individuals* available to all interested persons, this document is intended to be used as a checklist in assessing an agency's compliance with applicable standards. A line preceding each standard with which compliance may be assessed provides space for recording the agency's assessment using the code presented below or another code that the agency finds useful. (Standards that are merely prefatory statements are not preceded by such lines.) Agencies are encouraged to use the document in this way.

After first filing a formal Application for Survey, an agency seeking accreditation is required to submit one or more copies of the *Standards* in which it has indicated its assessments of compliance with all standards pertinent to the services and programs that it offers, using the following code:

1 full compliance with the standard
2 partial compliance with the standard
3 noncompliance with the standard
4 standard does not apply to the agency
5 activity or service required by the standard is provided by another agency within the agency's service delivery system

The agency's submission must include 1) its response to all standards identified in the *Standards* document as pertaining to all agencies and 2) its response to other standards in accordance with the particular services and programs that the agency does and does not provide, as reported in its Application for Survey.

An agency is in full compliance with a standard if all the requirements of the standard are met for each individual or situation to which the standard is applicable. Applicability or inapplicability of a standard is determined on the basis of requirements stated in the *Standards* and not on the basis of constraints that may be imposed on an agency's compliance. For example, a standard is inapplicable to an agency if the service or activity that it requires is not needed by the individuals the agency serves. A standard is not inapplicable merely because current practices, rules, regulations, personnel limitations, fiscal restrictions, or other constraints prevent compliance with it.

An agency that has applied for accreditation survey must also complete a *Survey Questionnaire*, which requires the agency to provide further information concerning its compliance with certain standards. The questionnaire also requires the agency to explain each response that indicates partial compliance with a standard (code 2) or inapplicability of a standard (code 4), and to identify the other agencies that provide services and programs required by the standards (code 5). The *Survey Questionnaire* (which any agency may purchase) includes detailed directions for its completion and a detailed description of the survey process.

Section 1
Individual Program Planning and Implementation

Definition

Individual program planning and implementation refers to the provision of systematic and organized services and interventions that are designed to enhance the development of a developmentally disabled individual. These services and interventions must be provided in accordance with a definite plan that is based on a determination of the individual's developmental status and needs.

Principles

The primary mission of each agency serving developmentally disabled individuals must be to provide and promote services that enhance the development of such individuals. Fulfillment of this mission requires:

- an interdisciplinary process for individual evaluation, program planning, and program implementation;
- assessment of the individual's developmental status and needs, as a basis for designing and maintaining a program that will enhance development;
- provision of services and interventions in accordance with developmental principles and the principle of normalization;
- effective coordination of services, reflecting planned and active participation of the developmentally disabled individual and, when appropriate, participation of the individual's family or advocate; and
- maintenance of functional records that are indispensable for effective programming.

1.1 The Interdisciplinary Process

Definitions

The interdisciplinary process is an approach to diagnosis, evaluation, and individual program planning and implementation in which professional and other personnel, including the individual being served and, when appropriate, the individual's family, participate as a team. Each participant, utilizing the skills, competencies, insights, and perspectives his or her training and experience provide, focuses on identifying the developmental needs of the individual and devising ways to meet them, without the constraints imposed by assigning particular domains of behavior or development to particular disciplines only. Participants share all information and recommendations, and develop, as a team, a single, integrated individual program plan to meet the individual's identified needs.

An extension of the interdisciplinary approach is the transdisciplinary approach, in which one or two members of an interdisciplinary team serve as team facilitators to implement the individual's program plan between regularly scheduled reevaluations by the team. Other members of the team teach and share their specialized professional skills with, and release their intervention roles to, the facilitator(s) during this period, while maintaining their professional or credentialed accountability. This approach was earlier called the cross-disciplinary or cross-modality method, due to the fact that different disciplines may be primarily concerned with different modalities, while the individual may require an integrated program utilizing several modalities.

Principles

The problems associated with developmental disabilities do not fall within the purview of any one discipline, but require for their alleviation the knowledge and skills of many professions. Therefore, services to developmentally disabled individuals must be rendered in an interdisciplinary manner.

The interdisciplinary approach requires that a unified and integrated evaluation and individual program plan be developed by an appropriately constituted team for each individual served. Consequently, the interdisciplinary team process requires participants to share and discuss, on a face-to-face basis, all information and recommendations, so that decisions can be made by the team, rather than merely by the individual members of it. Each participant in the interdisciplinary evaluation and program planning process, utilizing the skills, competencies, insights, and perspectives his or her training and experience provide, focuses on identifying the individual's developmental needs and devising ways to meet them.

The resulting information is pooled and reviewed by the team, and any necessary additional information is identified and obtained, so that an adequate plan can be devised. Individual members of the team then implement the programs for which they are assigned responsibility by the team, designing their detailed programs (for example, for education, speech therapy, or nursing care) in accordance with, and as elements of, the overall plan devised by the team. Periodically, team members providing services to the individual, as well as others whose participation is relevant to identifying the individual's needs and devising ways to meet them, must review the individual's progress toward the objectives developed by the team, reevaluate the individual's needs and the appropriateness of the individual's program in the light of his or her progress toward the objectives, and modify the objectives and/or the program accordingly.

The interdisciplinary process thus requires the direct participation of the person who is responsible for coordinating the individual's total program, and of the direct-contact persons who provide the individual's day-to-day care and programming, rather than merely the supervisors of such persons. Similarly, representatives of professions or programs should be those persons who work most directly with the individual, such as the individual's teacher or therapist, instead of only the supervisors of such persons, such as a principal or program director. At any given time the team should also include all other persons whose participation is relevant to identifying the needs of the individual and devising ways to meet them. Unless clearly unable or unwilling to participate, the individual being served should be a member of the team. The family of the individual should also participate, unless such participation is inappropriate, as in the case of an adult who does not wish the family to be involved. Agency procedures should encourage and facilitate the family's participation.

The persons working most directly with the individual may be thought of as the core members of the interdisciplinary team. To this core must be added such other persons as are necessary at any point in time. Part of the responsibility of the core members is to determine when other persons are needed in order to accomplish an adequate evaluation and program plan. The composition of the interdisciplinary team should always be determined by the needs of the particular individual being considered, rather than by any other factors. Agency procedures should specify responsibilities for participating on the team and for calling team meetings.

Because many identical or similar services or functions may be rendered competently by individuals of different professions, depending upon their knowledge and skills, there is no standard composition of an interdisciplinary team. Some professions, however, are represented more frequently than others. The initial core of the interdisciplinary team—those persons needed to initiate the evaluation of an individual upon admission or enrollment—may be standardized in an agency according to its main program emphasis. But part of the responsibility of such core members must be to identify other persons who are needed, and to secure their input and participation.

A major benefit of the interdisciplinary process is the ongoing education and role expansion of team members. Through face-to-face contact with representatives of other disciplines in a problem-solving setting, team members learn what other disciplines may contribute, and thereby increase their own skills and competencies. Consequently, it is important that a team, and especially the core members of a team, have access to all specialists who might contribute to evaluating and designing programs for the individuals being considered. Otherwise, the team members may never learn what a specialist can contribute and, therefore, never learn to call on such a person when the specialist's participation could be very helpful.

Agencies that procure substantial professional services from a variety of extramural sources, including individual practitioners and other agencies, sometimes encounter problems in implementing the face-to-face team meeting requirements of the interdisciplinary process. An agency, for example, may secure all medical services from private practitioners, perhaps the personal physicians of the individuals served. Or it may secure all psychological evaluation services from community clinics. In such situations, questions concerning face-to-face team discussion requirements should be answered by reference to the following principles:

1. The interdisciplinary evaluation process must provide for assembling, reviewing, and weighing the results of evaluations conducted by individual practitioners, so as to arrive at a comprehensive evaluation that identifies the individual's needs and establishes priorities for meeting them, when it is not possible to work on meeting all of them at once. A critical part of this process is determining, from the pooled results of individual evaluations, what other information is needed to develop an adequate plan. The face-to-face team meeting, therefore, should include as many as possible of the persons who conducted the evaluations being considered, and at least those

whose contribution—as core team-members or on the basis of an initial hypothesis—may be thought to be most relevant.

2. When the practitioner who conducted an evaluation is not present, someone on the team must be competent to interpret the report of the evaluation and to determine, in the light of other information reported to the team, whether the evaluation is adequate for identifying the individual's needs and designing a program to meet them, or whether additional information is needed.
3. Persons providing significant services to the individual, such as the individual teacher or therapist, should participate in face-to-face team meetings.
4. When special problems are present, every effort should be made to secure the face-to-face participation of the appropriate professional, rather than merely a report or recommendation. For example, it may not be necessary for a physician to participate in the team discussion if a competent person, such as a nurse, is present to interpret the physician's report and recommendations. However, if the individual's program includes the use of behavior-modifying drugs, the physician should be present, since no one can take the physician's place in contributing to a team review of such an individual's total program, which would include the possibility of modifying the individual's medication regimen. Again, if the individual manifests maladaptive behaviors that are serious enough to require the use of drugs, restraint, or time-out procedures, someone skilled in behavior management, such as a psychologist, should be present to participate in the team's discussion. In general, only (1) those reports of evaluations that can be interpreted adequately by others on the team and (2) those reports of programs that can be modified or adjusted by the team without the direct participation of the program-provider may be provided to the team only in written form or only by proxy.
5. Every effort should be made to secure, from time to time, the participation in team meetings of specialists who do not usually participate, in order to enhance the learning and role expansion function of the team.

Although members of the team must teach and share their specialized professional and service skills, they must also maintain their professional, credentialed, or licensed responsibility and accountability. There are matters and decisions that lie wholly within the realm of one profession: for example, only the physician may prescribe behavior-modifying drugs. As another example, the physician must determine the treatment for an individual's diabetes, although a nutritionist or dietitian may be involved in devising any prescribed diet, and other persons will be involved in serving the diet. Since being required to eat a special diet may well have effects on the individual and the individual's program, however, the team has to be informed of the diet and its medical necessity, and the team may need to address the diet's non-physiological effects. If a diet must be modified in consistency because of eating difficulties, persons other than the physician (for example, someone skilled in ways of teaching individuals to chew and swallow) should be involved. It is sometimes necessary to modify a diet (for example, by assuring that so-called finger foods are provided) to facilitate the development of self-feeding abilities. In such cases, the same procedure applies: consideration and decision by the team, followed by design and implementation of specialized programs or treatments by competent, qualified, and legally authorized persons.

Only rarely do the effects of a program in a seemingly circumscribed area, such as medical treatment, fail to extend to other areas of an individual's program. Even administrative decisions may have effects upon medical and other aspects of a program. Therefore, consideration and oversight of the entire program by an appropriately constituted interdisciplinary team is required.

To be effectively available to a developmentally disabled individual, services frequently need to be transdisciplinary in character. Developmentally disabled individuals may require a variety of sequential, developmental services that should be integrated into home or other residential programs, school services, other day services, and recreation services. For such individuals, agencies should design "modules" that permit such services to be delivered in a single setting, through the use of a transdisciplinary approach.

To provide a transdisciplinary approach, competent people, including parents, should share their skills and knowledge, without relinquishing professional accountability, so that services may be delivered in an integrated and effective manner within the individual's usual environment. The degree and amount of such services will vary with the age and needs of the individual served. The transdisciplinary approach may be particularly important for the infant and young child. An infant may not be able to tolerate excessive handling, but should not be denied the experience of the various developmental specialists who could be of help. A transdisciplinary team, wherein one member can help the family incorporate all parameters of the program, may be particularly desirable at this age.

When the child goes to school or is integrated into a day program, the need for ongoing transdisciplinary services, delivered within the center or the school, will continue. The transdisciplinary approach can prevent the child's missing educational or recreational programs while receiving restorative services. It should provide exposure to educators, recreation specialists, and other specialists, so that they may learn to integrate therapy into activities of daily living. While evaluation may have to be accomplished by individual specialists, with careful planning and with recognition of each discipline's interdependence on the other, the ongoing program can be delivered in a single setting.

The need for this degree of integration may not be as critical for adults moving into employment or day programs. This is partially due to the decreasing necessity for a daily regimen, and also takes cognizance of the need to approximate the normal life style prevailing in one's age group. Adjunctive and integrated services are important, however, in improving the adequacy of the individual's functioning in job-related activities, and the transdisciplinary approach may be especially useful for the adult with multiple disabilities. Vocational counselors, work supervisors, and therapists, for example, should work together to help the multiply disabled adult achieve adequate job skills.

Standards pertaining to all agencies

____1.1.1* An interdisciplinary team is identified for each individual served.

____1.1.2* Each individual's interdisciplinary team is constituted of persons drawn from, or representing, the professions, disciplines, or service areas that are relevant to identifying the individual's needs and designing programs to meet them.

____1.1.2.1* Each individual's interdisciplinary team includes those persons who work most directly with the individual in each of the professions, disciplines, or service areas that provide services to the individual.

____1.1.2.2* The interdisciplinary team process provides for and invites the active participation of the individual and, as appropriate, the individual's family and/or advocate.

____1.1.3* The agency has written policies and procedures that specify the organization and operation of the interdisciplinary team process as it pertains to the individuals served.

1.2 Evaluation and Assessment

Definitions

Evaluation and assessment is an empirical process that determines if, and to what degree, an individual has developmental deficits, and what interventions and services are needed to enable the individual to move toward increasingly independent functioning. Assessment identifies the individual's present developmental level; the individual's strengths, abilities, and developmental needs; the conditions that impede the individual's development; and where possible, the cause of the disability.

For assessment purposes, development may be conceptualized as having physical, sensorimotor, cognitive, communicative, social, and affective facets. Motor development means the development of those behaviors that primarily involve muscular, neuromuscular, or physical skills; and that involve varying degrees of physical dexterity. Sensory development includes the development of perceptual skills. Because sensory and motor development are intimately related, and because activities in these areas are functionally inseparable, attention to these two aspects of bodily activity is combined in the concept of sensorimotor development. Cognitive development refers to the development of those processes by which sensory input is received, transferred, stored, recovered, and used. It includes the development of the processes and abilities involved in recognizing, perceiving, reasoning, and remembering. Communicative development refers to the development of verbal and nonverbal, receptive and expressive communication skills. Social development refers to the formation and growth of those self-help and interpersonal skills that enable an individual to establish and maintain appropriate roles and fulfilling relationships within the environment. Affective or emotional development includes the development of behaviors that relate to, arise from, or influence one's interests, attitudes, values, and emotional expressions.

An individual's developmental status may also be conceptualized in terms of the adaptive behavior that the individual displays. Adaptive behavior refers to the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his or her age and cultural group. Meeting these standards requires specific adaptive behaviors, such as those pertaining to self-help and independent-living skills.

Principles

An individual assessment is necessary to develop an effective program plan. Interpretation of the tests and examinations that are needed for comprehensive diagnosis and assessment requires interdisciplinary teamwork. Systematic appraisal of the pertinent facts determined by an initial interdisciplinary assessment and by periodic reassessments should be the basis for all services offered to an individual. There should be a clear locus of responsibility for synthesizing, interpreting, and utilizing the results of the assessment components provided by different practitioners or agencies. The cultural and ethnic background of the individual should be given full attention in the selection and interpretation of the tests and examinations used. The agency should be fully cognizant of the life style of the individual and the family, and the time demands on the family during the assessment phase should be realistic.

Assessment must assure attention to the individual's overall development and total developmental needs. One way of assuring such attention is to conceptualize development as having physical, sensorimotor, cognitive, communicative, social, and affective facets, all of which must be encompassed by a comprehensive assessment conducted by an appropriately constituted interdisciplinary team. This does not mean, however, that an assessment must be structured or recorded according to this particular scheme or terminology, or that an identified assessment instrument or procedure must be employed for each of these aspects of development. A given instrument may assess development in several areas. For example, a scale of adaptive behavior, though employing different terminology, may encompass an individual's development and needs in each of the areas listed above. In every case, it is the comprehensiveness of attention to the individual's development and needs that is important, not the particular scale or terminology that may be used to delineate domains of development or behavior.

Evaluation and assessment, like other activities, must be carried out in accordance with the concept of using the least restrictive alternative. Individuals should not be separated from their familiar environments and admitted to unfamiliar settings for evaluation without compelling evidence that such separation and admission are essential for adequate assessment. Administrative convenience is not sufficient reason. The trauma of hospitalization or other institutionalization often results in changes in the individual's behavior and psychological condition. In this situation, assessment may be conducted during what is, in effect, an agency-provoked crisis, with results that are at least partially invalid.

Standards pertaining to all agencies

____1.2.1* The agency has a written statement that identifies for individuals served and their families those areas in which it is competent to offer assessment services.

____1.2.2 The agency has written procedures for referring the individual to other agencies for assessment services that it does not provide.

  ____1.2.2.1* The agency refers the individual to other agencies for assessment services that it does not provide, and follows-up on the completion of the referral.

____1.2.3* When assessments are provided by another agency, the results and recommendations are utilized in developing the individual program plan.

____1.2.4* Assessments are conducted without separating individuals from their residences overnight, unless such separation is necessary for adequate assessment.

____1.2.5* Assessments are provided by an interdisciplinary team constituted of members drawn from, or representing, such professions, disciplines, or service areas as are relevent in each particular case.

  ____1.2.5.1 An interdisciplinary team or a designated team member synthesizes, interprets, and provides guidance in utilizing, the assessment components provided by different practitioners or agencies.

1.2.6 The assessment of the individual includes attention to:

  ____1.2.6.1* physical development and health,

  ____1.2.6.2* sensorimotor development,

  ____1.2.6.3* communicative development,

  ____1.2.6.4* social development,

____1.2.6.5* affective development,

____1.2.6.6* cognitive development, and

____1.2.6.7* adaptive behaviors or independent-living skills.

1.2.7 The assessment process:

____1.2.7.1* identifies the presenting problems and disabilities and, where possible, their causes;

____1.2.7.2* identifies the individual's specific developmental strengths;

____1.2.7.3* identifies the individual's specific developmental needs;

____1.2.7.4* identifies the individual's needs for services, without regard to the actual availability of the services needed;

____1.2.7.5 identifies available alternatives for the selection of needed services; and

____1.2.7.6 documents a locus of responsibility for identified needed services.

1.2.8 The assessment process includes:

____1.2.8.1* physical examination and health assessment;

____1.2.8.2* dental evaluation;

____1.2.8.3* medication history;

____1.2.8.4* evaluation of nutritional status;

____1.2.8.5* visual screening, and

    ____1.2.8.5.1* comprehensive visual assessment when indicated by screening results;

____1.2.8.6* auditory screening, and

    ____1.2.8.6.1* comprehensive audiological assessment when indicated by screening results, including tests of pure-tone air and bone conduction, speech audiometry and other audiometric procedures as necessary, assessment of use of visual cues, and assessment of use of amplification;

____1.2.8.7* speech and language screening, and

    ____1.2.8.7.1* comprehensive speech and language evaluation when indicated by screening results, including appraisal of articulation, voice, rhythm, and language;

____1.2.8.8* social assessment; and

____1.2.8.9* educational, vocational, psychological, or developmental assessments, as appropriate for the individual, as determined by the interdisciplinary team.

1.2.9 Reports of physical examinations include:

____1.2.9.1 all pertinent findings and recommendations resulting from an assessment of all systems of the body;

____1.2.9.2* attention to the individual's ability to see and to hear;

____1.2.9.3* routine screening laboratory examinations, as determined by the physician, and special studies when the index of suspicion is high;

____1.2.9.4 review of immunization status; and

____1.2.9.5 assessment of the individual's health maintenance skills.

____1.2.10* The agency provides or obtains additional specialized assessments as needed.

1.2.10.1 Assessment services for individuals with seizure disorders include access to:

____1.2.10.1.1* electroencephalographic services meeting the 1976 standards of the American Electroencephalographic Society;

____1.2.10.1.2* laboratory services that provide blood drug level examinations and that participate in a nationally-monitored quality control program; and

____1.2.10.1.3 special diagnostic in-patient services for individuals with seizures that are difficult to control.

1.2.10.2 Evaluation of the individual's nutritional status includes:

____1.2.10.2.1 determination of dietary requirements and assessment of intake and adequacy through dietary interview, clinical evaluation, and biochemical assessment;

____1.2.10.2.2 assessment of food service practices in relation to the individual's nutritional status;

____1.2.10.2.3 assessment of feeding practices and eating skills, capabilities, and potentials; and

____1.2.10.2.4 evaluation of the total food intake of the individual, including food consumed outside of, as well as within, the agency.

____1.2.11* Assessment necessary to develop the initial program plan is completed within 30 calendar days after enrollment.

____1.2.11.1* The assessment process includes review and updating, as necessary, of evaluations made prior to enrollment.

1.2.12 Reassessments are provided or obtained:

____1.2.12.1* at times of crisis, and

____1.2.12.2* when behavioral responses indicate the need.

____1.2.12.3* Each individual receives an assessment annually, or when otherwise determined by the interdisciplinary team, that includes educational, vocational, psychological, or developmental assessment, as determined by the team.

____1.2.12.4* Health assessments, including physical examination and dental evaluation, are provided or obtained at regular intervals, but at least annually.

1.2.12.5 Children under the age of ten receive:

____1.2.12.5.1 annual audiometric screening; and

____1.2.12.5.2 annual speech and language screening, if indicated.

____1.2.13* The assessment process is adapted to the cultural background, language, and ethnic origin of the individual and the family.

1.2.14 It is documented that:

____1.2.14.1* the individual and, when appropriate, the individual's family and/or advocate are involved in the assessment process, or that efforts to involve them have been made;

____1.2.14.2* assessment findings are interpreted to the individual and, when appropriate, to the individual's family and/or advocate; and

____1.2.14.3* assessment findings are interpreted, in terms of actions to be taken, to the persons responsible for carrying out the individual's program.

____1.2.15* Assessment findings are recorded in terms that facilitate clear communication across disciplines and with individuals served.

____1.2.16* With appropriate written permission and with adherence to other requirements concerning confidentiality that are detailed in Section 3.1, assessment reports are sent to other agencies that provide services to the individual and/or the individual's family.

1.3 The Individual Program Plan

Definition

The individual program plan is a written plan of intervention and action that is developed on the basis of assessment results and modified at frequent intervals, with the participation of all concerned. It specifies goals and objectives and identifies a continuum of development, outlining projected progressive steps and the developmental consequences of services.

Principles

An individual program plan must be developed for each individual accepted for service, regardless of the individual's chronological age or developmental level. The plan should be based on individual assessment findings and on any other information that assists in understanding the individual's situation. Relevant staff of the agency serving the individual should develop the plan with the participation of the individual, unless the individual is clearly unable or chooses not to participate, the family, unless their participation is inappropriate, and the staff of other agencies involved in serving the individual. A plan developed by another agency prior to the onset of services should be reviewed to determine its relevancy to the current needs of the individual, and updated as appropriate. Goals and objectives should be stated separately and a time frame should be specified for their achievement. Goals and objectives must be expressed in behavioral terms that provide measurable indices of progress, and that enable the effectiveness of interventions to be evaluated. Modes of intervention for the achievement of the stated objectives must be specified, and agencies capable of delivering the needed services should be identified. The individual program plan must be modified as goals and objectives are, or are not, attained. Review and appropriate revision of the plan must be a continuous and self-correcting process. The plan must help all concerned to coordinate their efforts and activities, so as to maximize services to the individual.

Standards pertaining to all agencies

____1.3.1* Each individual enrolled has an individual program plan.

  ____1.3.1.1* The initial individual program plan is developed within 30 calendar days after the individual is enrolled in a service.

  ____1.3.1.2* A plan developed by another agency prior to enrollment is reviewed to determine its relevancy to the current needs of the individual, and is updated as necessary, within 30 calendar days after enrollment.

____1.3.2* The individual program plan is developed by an appropriately constituted interdisciplinary team.

  1.3.2.1 The individual program plan is developed with the participation of:

    ____1.3.2.1.1* the individual, unless the individual's inability or unwillingness to so participate is documented;

____1.3.2.1.2* the individual's family, unless it is documented that such participation is inappropriate or unobtainable;

____1.3.2.1.3* the individual's advocate, if appropriate;

____1.3.2.1.4* all relevant agency staff members; and

____1.3.2.1.5 staff of other agencies involved in serving the individual.

____1.3.3* The individual program plan states specific objectives to reach identified goals.

____1.3.3.1* The objectives in the individual's program plan reflect the individual's developmental needs, as identified in assessment data as required in Section 1.2.

1.3.3.2 The objectives of the individual program plan are:

____1.3.3.2.1* stated separately (that is, each objective is stated in terms of a single behavioral outcome),

____1.3.3.2.2* assigned projected completion dates,

____1.3.3.2.3* expressed in behavioral terms that provide measurable indices of progress,

____1.3.3.2.4* sequenced within a developmental progression appropriate to the individual, and

____1.3.3.2.5* assigned priorities.

____1.3.4* The individual program plan specifies activities for the achievement of the stated objectives.

____1.3.4.1 The individual program plan describes the barriers to the achievement of the objectives.

____1.3.5* The individual program plan is written in terms that are understandable to all concerned.

____1.3.6* When implementation is a shared responsibility, the individual program plan identifies the agencies or persons responsible for delivering the services required.

____1.3.6.1 The individual program plan includes a written agreement that specifies the role and responsibilities of each participant in implementing the plan, including the individual, unless the individual's inability or unwillingness to so participate is documented.

____1.3.6.2 The agency assists the individual and the family in establishing and maintaining any records necessary to document their roles in implementing the individual program plan.

____1.3.7* The ongoing implementation and continuing appropriateness of the individual program plan is reviewed at least monthly by a member or members of the individual's interdisciplinary team, as determined by the team.

____1.3.7.1* The individual's response to activities designed to achieve at least those objectives identified as having priority is recorded in behavioral terms at intervals determined by the interdisciplinary team, but at least monthly.

____1.3.7.2 Problems and/or changes that call for review of the individual program plan by the interdisciplinary team are documented.

____1.3.7.3* The team is convened to review the individual program plan when problems and/or changes that call for review by the team are indicated.

____1.3.8* The individual program plan is reviewed by the individual's interdisciplinary team at intervals determined by the team, but at least annually. The review:

____1.3.8.1* assesses the individual's response to activities designed to achieve the objectives stated in the individual program plan,

____1.3.8.2* modifies the activities and/or the objectives as necessary,

____1.3.8.3* determines the services that are needed, and

____1.3.8.4* includes consideration of the advisability of continued enrollment and/or alternative placements.

1.3.8.5 The results of the review of the individual program plan by the interdisciplinary team are:

____1.3.8.5.1* interpreted to the individual, when appropriate;

____1.3.8.5.2.* interpreted to the individual's family, when appropriate;

____1.3.8.5.3* interpreted to the individual's advocate, if appropriate; and

____1.3.8.5.4* made available to relevant personnel.

1.4 Individual Program Implementation

Definition

Individual program implementation refers to the provision of services in accordance with the individual program plan.

Principles

While every individual possesses the potential for growth and development, specific opportunities must be provided if optimal growth and development are to occur. Effective programs for developmentally disabled individuals must be based upon developmental principles, including the following:

1. Development begins at conception and continues throughout the life span of every human being.
2. Normally, human development progresses in a sequential, orderly, and predictable manner. Consequently, developmental sequences can be identified and used in planning programs and assessing progress.
3. The rate and direction of development may be significantly modified by utilizing and controlling certain physical, psychological, and social aspects of the individual's environment.

These principles constitute the "developmental model," as contrasted with the deficit or illness model on which programs for developmentally disabled persons have often been based.

Opportunities to learn and develop must be available to every developmentally disabled individual, regardless of age or type or degree of disability. Such opportunities must be provided in accordance with the principle of normalization, which means helping developmentally disabled persons to develop and maintain behaviors and characteristics that are as culturally normative as possible, utilizing means that are as culturally normative and least restrictive as possible. The principle of normalization is intimately related to the developmental model, inasmuch as it specifies both the goals of developmental programs and the means of achieving these goals. Programs must be designed to foster those behaviors that maximize the human qualities of individuals, increase the complexity of their behavior, and enhance their ability to cope with their environments. Individuals should be enabled to develop an increasing degree of control over their environments, including other people and themselves, which implies that the individual must have the opportunity to make choices and the freedom to explore and interact with the environment.

In order to realize the potential of each developmentally disabled individual, attention must be directed to each individual's total developmental needs, as identified by comprehensive assessment and addressed in the individual program plan. Such attention must be reflected in objectives that are expressed in terms of accomplishing developmental tasks or achieving adaptive behaviors or independent-living skills. Particular developmental tasks may be primarily identified with, or represent primary objectives of, the developmental stages of infancy, childhood, adolescence, and adulthood, or program settings characterized as education, recreation, or work. Development, however, is essentially indivisable and continuous. Therefore, the accomplishment of developmental tasks and the achievement of adaptive behaviors and independent-living skills must not be identified with particular chronological ages or program settings only. Developmental programs designed to meet the identified needs of developmentally disabled individuals must be available to such individuals throughout their lives.

Standards pertaining to all agencies

____1.4.0.1* The agency provides or obtains a continuum of education, training, and retraining programs, in accordance with the needs of individuals served.

____1.4.0.2* If developmental programs that begin in infancy and continue throughout the life span are not available, the agency documents its efforts to initiate them.

____1.4.0.3* Programs are determined by the developmental needs of the individuals served and are not contingent on age or time restrictions.

____1.4.0.4* The agency utilizes, as extensively as possible, generic services and resources appropriate to the needs of the individuals served, including integrating individuals in the environments available in the community that are most appropriate to their needs.

____1.4.0.5* Services are provided in settings that are appropriate to the chronological ages and developmental levels of the individuals served.

____1.4.0.6 The agency's programs provide ongoing opportunities for, and encourage disabled individuals to experience, relationships with nondisabled persons in community activities.

1.4.1 Physical Development and Health

Definitions

The health needs of developmentally disabled individuals include the needs for health care that are common to all persons, plus the special health needs that arise from problems associated with developmental disabilities. Health includes both physical and mental health.

Principles

Although developmentally disabled individuals have the same basic needs for health care as other people, they are at risk for a higher incidence of special health needs that, if ignored, seriously endanger their potential development and performance. Because the psychological and financial impact of the disability upon the family may inhibit their seeking and appropriately utilizing services, agencies and advocates have a responsibility to promote prevention and early detection of disabilities, and to mobilize the services of all generic resources to remediate them. Adequate and continuous health supervision, early detection and remediation of disabling conditions, and an individual program plan to enhance development, are essential in helping the developmentally disabled individual maintain optimal health, overcome barriers to learning, discover new possibilities for training, improve self-image, and enhance acceptance by the family and the community. Every community resource concerned with meeting basic life needs, promoting good health, and remediating disabilities, on behalf of the population as a whole, should be equally available and accessible to developmentally disabled individuals. Generic services in the community should provide for such individuals, and these services should be modified when necessary to meet their special needs.

Standards pertaining to all agencies

____1.4.1.1* The agency has written procedures for the prevention of health problems, for health maintenance, and for early detection and remediation of the health needs of the individuals served.

____1.4.1.1.1 Health supervision conforms to current recognized standards of health care, such as the *Standards of Child Health Care of the American Academy of Pediatrics*, 3rd edition, 1977.

____1.4.1.2* Each individual has a primary physician who maintains familiarity with the individual's state of health and with conditions that bear on it (including, in the case of an individual enrolled in a residential program, conditions in the residence).

1.4.1.3 Preventive health services include:

____1.4.1.3.1* immunizations, using as a guide the recommendations of the state health department; the *1972 Collected Recommendations of the U.S. Public Health Service Advisory Committee on Immunization Practices*, as revised by supplements; or the *Report of the Committee on Infectious Diseases of the American Academy of Pediatrics*, 18th edition, 1977;

____1.4.1.3.2* tuberculosis control, in accordance with recommendations such as those in the 1974 statement of the Section on Diseases of the Chest of the American Academy of Pediatrics, as appropriate to the individuals served;

____1.4.1.3.3* surveys for the detection and prevention of communicable diseases; and

1.4.1.3.4 a comprehensive preventive dentistry program that includes:

____1.4.1.3.4.1 fluoride therapy, including fluoridation of the agency's water supply and/or topical and systemic application as prescribed by a dentist;

____1.4.1.3.4.2 provision for comprehensive daily plaque control (tooth brushing and flossing);

____1.4.1.3.4.3 provision for periodic monitoring of oral hygiene measures by a dentist or dental hygienist;

____1.4.1.3.4.4 provision for oral prophylaxis as needed;

____1.4.1.3.4.5 provision for optimum therapeutic care to prevent the development and/or progression of caries, periodontal, and other oral diseases; and

____1.4.1.3.4.6 imparting information regarding nutrition and diet control measures to individuals served and staff.

____1.4.1.4* Services are provided or obtained for the detection, diagnosis, and treatment of sensorimotor deficits.

____1.4.1.5* The agency provides or obtains corrective, orthotic, and prosthetic devices, in accordance with specialists' recommendations.

____1.4.1.5.1* The agency provides or obtains periodic reevaluation of corrective, orthotic, and prosthetic devices by appropriate professional personnel to ascertain their continued applicability and fitness, and to recommend changes as needed.

____1.4.1.5.2 The agency provides or obtains instruction for the individual, the family, and pertinent staff members in the proper use and care of all corrective, orthotic, and prosthetic devices.

____1.4.1.5.3* Mechanical supports used in normative situations to achieve proper body position and balance are employed only as an integral part of an individual program plan that is designed by the individual's interdisciplinary team. Such supports are:

____1.4.1.5.3.1* designed, and their use monitored, by a qualified professional person;

____1.4.1.5.3.2* applied by staff trained by a qualified professional person; and

____1.4.1.5.3.3* designed and applied with concern for principles of good body alignment, concern for circulation, and allowance for change of position.

____1.4.1.5.3.4* Each program plan that includes utilization of mechanical support specifies the reason for the support, the situations in which it is to be applied, and the length of time for which it is to be applied.

____1.4.1.6* The agency provides or obtains other specialized health services for individuals in need.

____1.4.1.6.1 Provision for dental treatment includes, as indicated, the dental specialties of pedodontics, orthodontics, periodontics, prosthodontics, endodontics, oral surgery, and oral medicine.

____1.4.1.6.2 Home health services are provided or obtained to implement home aspects of prevention or remediation of illness or disability.

____1.4.1.6.3 Specialized family planning services are provided or obtained for individuals and their families.

____1.4.1.6.4 Genetic counseling services are provided or obtained for individuals and their families.

1.4.1.6.5 Medical services for individuals with seizure disorders include:

____1.4.1.6.5.1* provisions adequate for determining the cause and nature of the disorder, including family and developmental histories, neurological evaluation, accurate subjective and objective descriptions of seizures, and appropriate laboratory tests; and

____1.4.1.6.5.2* services to achieve control of seizures, including reliable and accurate records of seizure activity; charting of anticonvulsant drugs; periodic determination of anticonvulsant drug level; and case review, at individually determined intervals, by personnel specifically trained in the management of individuals with seizure disorders.

____1.4.1.7 Nutritional services are provided or obtained in order to assist in planning adequate diets to meet the dietary needs of individuals, including modifications of diets in consistency or nutrient content and consideration of the nutrient value of food consumed between meals. (See also standards 4.6.7.2-5.)

1.4.1.7.1 Appropriate dietary modifications are made to:

____1.4.1.7.1.1 provide for the development of functional oral systems (sucking, swallowing, chewing), and

____1.4.1.7.1.2 promote normal evacuation and urination.

1.4.1.7.2 Modified diets are:

____1.4.1.7.2.1* prescribed by the individual's interdisciplinary team, with a record of the prescription kept on file; and

____1.4.1.7.2.2* periodically reviewed and adjusted, as needed.

____1.4.1.7.3* Individuals eat in an upright position or in the position that either best facilitates functioning of muscles involved in swallowing, or is medically indicated.

____1.4.1.8* Individuals who are incontinent are bathed or cleansed immediately upon voiding or soiling, with due regard for privacy, and all soiled items are changed, unless specifically contraindicated by the toilet training program in which they are enrolled.

____1.4.1.8.1* Persons wash their hands after assisting an incontinent individual.

____1.4.1.9* Individuals who have not learned to obtain a drink of water independently are given the proper daily amount of fluid at appropriate intervals to prevent dehydration.

____1.4.1.10* Each individual's weight is recorded at least quarterly, and individuals with special needs are weighed more frequently.

____1.4.1.10.1* Each individual's height is recorded quarterly until the age of maximum growth.

____1.4.1.10.2* Until the age of maximum growth, weight and height records are maintained on standard graphic forms that permit ready reference to norms.

____1.4.1.10.3* The agency documents its efforts to assist individuals in maintaining their normal weights.

____1.4.1.11* The agency has a written policy regarding the administration of all medication used by individuals, including medication that is not specifically prescribed by the attending practitioner. The policy includes provisions concerning the:

____1.4.1.11.1* self-administration of medication;

____1.4.1.11.2* specification, by title or by level of training, and in accordance with state law, of the personnel authorized to administer various classes of drugs;

____1.4.1.11.3* routine of drug administration, including standardization of abbreviations relevant to administration; and

____1.4.1.11.4 reporting of medication errors and drug reactions.

____1.4.1.12* No medication is administered to an individual without a written or verbal order by a physician or other legally authorized person.

____1.4.1.12.1 Verbal orders are authenticated in accordance with the agency's written policy.

____1.4.1.13* Drugs are administered only by persons authorized to do so.

____1.4.1.14* There are automatic calendar-date stop orders on all drugs.

____1.4.1.15* Medications are used only by the individual for whom they were issued.

____1.4.1.16* Each drug is identified up to the point of administration.

____1.4.1.17* The unit dose or individual prescription system of drug distribution is used.

____1.4.1.18* Medication errors and drug reactions are recorded and reported immediately to the person responsible for supervision of the agency.

____1.4.1.18.1 Medication errors are administratively evaluated and appropriate corrective action is taken.

____1.4.1.19* Each individual who requires medication receives medical supervision, which includes regular evaluation of the individual's response to the medication, including appropriate monitoring and laboratory assessment.

____1.4.1.19.1 A drug treatment plan, as prescribed by the attending physician, is prepared by the responsible pharmacist for inclusion in the individual's record and for use by the staff. The plan includes:

____1.4.1.19.1.1 the drug product, dosage form, route of administration, and time of administration, including, when appropriate, the time with respect to meals, other drugs, and activities;

____1.4.1.19.1.2 a schedule of laboratory tests necessary to detect adverse reactions; and

____1.4.1.19.1.3 noting, for the staff's information, any potential adverse reactions.

____1.4.1.19.2* The record of each individual receiving medication includes a current medication response profile that provides a record of all medications dispensed and the individual's response to them.

____1.4.1.20* The agency implements written policies and procedures, appropriate to the needs of the individuals being served, concerning detection of signs of injury, disease, and abuse.

____1.4.1.21* The agency has a written policy that specifies the procedures to be followed in medical emergencies and in rendering emergency medical care.

____1.4.1.21.1* The telephone number of the applicable poison control center is posted.

____1.4.1.22* The agency's policies and procedures for the care of individuals with infectious and contagious diseases conform to state and local health department regulations.

____1.4.1.22.1 Copies of the agency's policies and procedures concerning the care of individuals with infectious and contagious diseases are provided to staff, individuals served, and families.

1.4.2 Mobility

Definition

Mobility is the ability of the individual to move within, and thereby interact with, the environment.

Principles

Mobility enhances the individual's opportunities for development. Improved mobility contributes to socialization, to the development of adaptive behaviors and self-care skills, to better appearance and attitude, to improved physical functioning, and to more satisfying use of leisure time. Services to enhance mobility should include helping nonambulatory individuals to become mobile or partially mobile, as well as enabling them to use public and private transportation systems to meet their normal needs and to secure access to needed programs and services. When disabled individuals find existing modes of transportation to community services difficult or impossible, modification of the modes of transportation should be initiated.

Facilities must be accessible to, and usable by, nonambulatory and multiply handicapped individuals, so that individuals are not denied, solely because of physical handicaps, services or programs that are otherwise appropriate for them. If the agency does not provide such accessibility because it does not serve individuals for whom special facilities and equipment are necessary, there should be evidence that such individuals receive appropriate services elsewhere within the service delivery system. In the absence of such evidence, the agency's plans for expansion should include plans for making at least a suitable proportion of its facilities accessible to, and usable by, nonambulatory and multiply handicapped individuals.

.*Standards pertaining to all agencies*

____1.4.2.1* The agency provides or obtains services and equipment to increase the mobility of individuals served, as specified in their individual program plans.

____1.4.2.2* Individuals served, staff, and volunteers are instructed in the safe use of mobility devices and procedures.

  ____1.4.2.2.1* All equipment used in the mobility program is in proper working condition.

____1.4.2.3* The agency's buildings and outdoor recreation facilities meet A.N.S.I. Standard Number A117.1—1961 for making buildings accessible to physically handicapped persons, unless another edition of the standard is prescribed by the state authority having jurisdiction. All buildings provide:

  ____1.4.2.3.1* entrance ramps wide enough for use by individuals in wheelchairs, not exceeding a rise of one foot in twelve, with nonslip surfaces and with rails on both sides;

  ____1.4.2.3.2* doorways and corridors wide enough for use by individuals in wheelchairs; and

  ____1.4.2.3.3* grab bars in toilet and bathing facilities.

1.4.2.3.4 In each program area or living unit, at least one of each of the following is accessible to, and usable by, individuals in wheelchairs:

____1.4.2.3.4.1* drinking unit (a means of obtaining drinking water),

____1.4.2.3.4.2* toilet,

____1.4.2.3.4.3* lavatory, and

____1.4.2.3.4.4 telephone (if a telephone is provided for use by ambulatory individuals).

____1.4.2.3.5 Multistory buildings are equipped with elevators or with other means, as are used by the general public, of making accessible to nonambulatory individuals all floors to which they need access.

____1.4.2.4 Driver education is available to those individuals who are capable of learning to drive.

____1.4.2.5* There is evidence that the agency is promoting or helping to establish generic community transportation services that are usable by disabled individuals.

____1.4.2.6* The agency assists individuals in securing transportation that enables them to have access to needed programs and services.

____1.4.2.6.1 The agency assists in securing transportation needed by individuals after hours and on weekends.

1.4.2.7 The transportation system operated by, or under contract to, the agency meets the following criteria:

____1.4.2.7.1 it is licensed by a state agency, when such licensure is available;

____1.4.2.7.2* a current state inspection report is available, when such inspection is provided;

____1.4.2.7.3* adequate insurance coverage, including comprehensive, liability, and property damage, is in force;

____1.4.2.7.4* overloads are not permitted;

____1.4.2.7.5 vehicles are appropriate to the agency's purposes and do not unnecessarily stigmatize the individuals served; and

____1.4.2.7.6* vehicles used to transport physically handicapped individuals are adapted to their needs.

1.4.3 Habilitation, Education and Training

Definitions

Habilitation is the process by which the staff of an agency assists individuals to acquire and maintain those life skills that enable them to cope more effectively with the demands of their own persons and of their environments, and to raise the levels of their physical, mental, and social functioning. Habilitation includes, but is not limited to, programs of formal, structured education and treatment; and habilitation encompasses, in addition to activities addressed in this section, interventions described elsewhere in this document. Education is a socially directed process to facilitate learning and development through deliberate interventions. Training refers to an organized program for acquiring, improving, or maintaining a particular skill.

Principles

Efforts to realize the potential of the developmentally disabled individual must be expressed in objectives and provisions for the accomplishment of developmental tasks or the achievement of adaptive behaviors or independent-living skills. Because it may not be possible to attempt to fulfill all of the individual's developmental needs simultaneously, it may be necessary for the individual's interdisciplinary team to identify those needs and objectives that have priority, and to arrange the individual's program accordingly. Training programs must be systematic, and the content of each program must be specific to the individual's needs, as reflected in the individual program plan. Acquisition of skills and competencies should be planned to result in improved self-image and self-esteem.

Standards pertaining to all agencies

____1.4.3.1* Training in self-help, independent-living, and other skills is developed and implemented for each individual, in accordance with the individual's needs, as assessed and identified as priorities by the individual's interdisciplinary team. Such training includes, but is not necessarily limited to, the areas of:

____1.4.3.1.1 eating and drinking (including table manners, use of adaptive equipment, and use of drinking units);

____1.4.3.1.2 toileting (including use of equipment);

____1.4.3.1.3 personal hygiene (including washing, bathing, shampooing, brushing teeth, and menstrual care);

____1.4.3.1.4 dressing (including purchasing, selecting, and having access to clothing);

____1.4.3.1.5 grooming (including shaving, combing and brushing hair, and caring for nails);

____1.4.3.1.6 health care (including skills related to nutrition, use and self-administration of medication, first aid, care and use of prosthetic and orthotic devices, preventive health care, and safety);

____1.4.3.1.7 communication (including language development and usage; signing; use of the telephone; letter writing; and availability and utilization of communication media, such as books, newspapers, magazines, radio, television, telephone, and such specialized equipment as may be required);

____1.4.3.1.8 interpersonal and social skills (including sharing, courtesy, cooperation, and responsibility; and age-appropriate and culturally normative social behaviors and relationships involving peers of the same and different sex, younger and older persons, and persons in authority);

____1.4.3.1.9 home management (including maintenance of clothing, shopping, meal planning and preparation, and housekeeping);

____1.4.3.1.10 employment and work (see Section 1.4.4);

____1.4.3.1.11 mobility (including ambulation, transportation, mapping and orientation, and use of mobility equipment; see also Section 1.4.2);

____1.4.3.1.12 time management (including management of leisure time);

____1.4.3.1.13 financial management;

____1.4.3.1.14 use of leisure time (see Section 1.4.5);

____1.4.3.1.15 academic and preacademic skills (including attention, discrimination, association, and memory; and number, time, and spatial concepts);

____1.4.3.1.16 motor and perceptual skills (including balance and posture, and gross and fine motor skills);

____1.4.3.1.17 problem-solving and decision-making (including opportunities to experience consequences of decisions);

____1.4.3.1.18 human sexuality; and

____1.4.3.1.19 aesthetic appreciation.

1.4.3.2 Each training program specifies:

____1.4.3.2.1* the behavioral objectives of the training;

____1.4.3.2.2* the methods to be used;

____1.4.3.2.3* the training schedule;

____1.4.3.2.4* the person(s) responsible for conducting the training; and

____1.4.3.2.5* the data to be collected to assess progress toward the objectives.

1.4.3.3. Each training program:

____1.4.3.3.1 utilizes methods and materials that are culturally normative and appropriate to the developmental level and chronological age of the individual, unless the use of nonnormative or non-age-appropriate methods and materials is justified in the individual's program plan;

____1.4.3.3.2 reflects, or makes provisions for providing or obtaining, direct or consulting services from those professionally qualified persons necessary to assist the family and the staff in conducting training;

____1.4.3.3.3 identifies other programs and services, including those provided by other agencies or resources, that are available to the individual or the family to supplement the individual's training program; and

____1.4.3.3.4 includes, if appropriate, a program developed with the individual's family for its use, in accordance with its role in implementing the individual program plan.

1.4.3.4 To facilitate training:

____1.4.3.4.1* food is served in a form consistent with the individual's developmental needs;

____1.4.3.4.2* individuals eat in a manner consistent with their developmental needs;

____1.4.3.4.3* individuals are fed at a leisurely rate, and the time allowed for eating permits adequate nutrition, promotes the development of self-feeding abilities, encourages socialization, and provides a pleasant mealtime experience;

____1.4.3.4.4 staff members are encouraged to eat with those individuals who have semi-independent or independent-eating skills;

____1.4.3.4.5 dining arrangements are based upon a rational plan to meet the needs of the individuals served and the requirements of their programs;

    ____1.4.3.4.5.1 dining and serving arrangements provide for a variety of eating experiences (for example, cafeteria and family style) and, when appropriate, for the opportunity to make food selections with guidance;

    ____1.4.3.4.5.2 unless justified on the basis of meeting the program needs of the individuals being served, dining tables seat small groups (typically, four to six at a table), perferably including both sexes;

____1.4.3.4.6* dining areas are equipped with tables, chairs, eating utensils, including adaptive utensils, and dishes designed to meet the developmental needs of each individual;

____1.4.3.4.7* individuals' clothing is appropriate to their chronological ages, considering cultural norms and personal choice, unless contraindicated by decision of the interdisciplinary teams responsible for their programs, as documented in their individual program plans;

    ____1.4.3.4.7.1* each individual's clothing is designed to facilitate training in needed self-help skills;

____1.4.3.4.8* appropriate equipment is provided for toilet training, including equipment appropriate for multiply handicapped individuals; and

____1.4.3.4.9* menstrual supplies are of the same quality and diversity available to all women.

1.4.4 Work and Employment

Definition

Work and employment refers to services that enable each individual to develop as far as possible along a continuum from vocational afunction to remunerative employment and entry into the mainstream of society as an independent citizen and worker. Such services include vocational evaluation, general and specific work training and work-related activities, and specific employment opportunities. Employment exists when an individual has been placed in a production or service setting. Employment requires that the individual receive remuneration for work produced, usually on the basis of an agreement between the employee and the employer, and consistent with applicable law.

Principles

Each individual should have the opportunity to prepare for, and to engage in, work and employment, although the worth of an individual is not to be determined by the individual's ability or inability to work, and placement in sheltered employment should have status equal to placement in competitive industry. Each individual should be provided with a basic orientation to the "world of work," including opportunities for, and the purpose, value, and necessity of, work. Work evaluation and assessment services should be provided to each individual in order to objectively identify the individual's interests, capabilities, and potential. The work evaluation process should identify those individuals who are not yet ready to benefit from participation in employment and work programs. Such individuals should receive services that are appropriate to their developmental needs and that may be provided in nonwork settings. Methods of bioengineering, specialized equipment design, and environmental modification should be applied to broadening the vocational potential of the individual.

Evaluation and assessment procedures should be standardized, reliable, and valid. Assessment systems that prescribe training procedures to maximize vocational functioning in sheltered or competitive settings should be devised for severely handicapped persons for whom vocational training has typically been considered to be unfeasible. Evaluation results should be recorded precisely, so that data can be used with confidence when formulating the individual's work plan. Individual employment and work plans should reflect a comprehensive approach to work preparation and should identify both the facilitators and inhibitors of learning outcomes. Work training, both general and job specific, should be commensurate with individual ability and potential, and should be directed toward the achievement of the attitudes, skill levels, knowledge, and adaptability needed for employment. Training curricula should be time-framed and should specify methodologies, materials, and outcomes. Types of work should not be sexually or racially stereotyped, and training materials should emphasize occupations and jobs being held by both sexes. Training should also provide work-related skills needed to deal effectively with the social and affective expectations associated with work. Individual job placement and follow-along should assure that the individual will work in a suitable environment and that the individual will be provided with technical assistance in adjusting to the requirements of the job.

Standards pertaining only to agencies providing or obtaining work and employment services

____1.4.4.1* The objective of the agency's work and employment services is to assist each individual to move as far as possible along the continuum from vocational afunction to remunerative employment and entry into the mainstream of society as an independent citizen and worker.

____1.4.4.1.1 Work training and employment provided or obtained by the agency are structured in such a manner as to provide the variety and graduated complexity of learning experiences necessary to accommodate the range of work potential existing within the group of individuals being served.

____1.4.4.2* The agency provides a program of orientation to work and employment. Orientation activities include, but are not necessarily limited to:

____1.4.4.2.1 the purpose, value, and necessity of work;

____1.4.4.2.2 the agency's program and other available programs that offer services to support work needs;

____1.4.4.2.3 characteristics of work environments;

____1.4.4.2.4 job opportunities, availability, and risks;

____1.4.4.2.5 salary expectations and fringe benefits;

____1.4.4.2.6 work-related activities; and

____1.4.4.2.7 vocational exploration opportunities.

1.4.4.3 The agency provides or obtains work evaluation and assessment that include, as appropriate to the individual:

____1.4.4.3.1* determining work interests,

____1.4.4.3.2* measuring the individual's general and specific work abilities,

____1.4.4.3.3* measuring the individual's task performance and proficiency levels,

____1.4.4.3.4* interpreting and utilizing comprehensive individual assessment data in a way that is relevant to the individual's work needs, and

____1.4.4.3.5* assessing attitudes and adaptibility needed for employment.

____1.4.4.4* The agency utilizes work evaluation and assessment data to determine the training or employment programs appropriate for the individual.

____1.4.4.4.1* The agency's work evaluation and assessment process is standardized so that individual performance is evaluated against norms.

____1.4.4.4.2* Individual work performance records are organized and maintained so as to provide precise data for designing the individual work plan.

____1.4.4.5* The agency ensures, through ongoing review of the labor market, that its work training and employment procedures and placement objectives are current and relevant.

1.4.4.6 Work training includes, but is not necessarily limited to:

____1.4.4.6.1 work activities training that provides therapeutic benefits enhancing the development of the individual,

____1.4.4.6.2* training that develops skills specific to identified jobs,

____1.4.4.6.3* work adjustment training that develops appropriate attitudes and work habits,

____1.4.4.6.4* on-the-job training that leads to placement in a specific job, and

____1.4.4.6.5* training and sheltered production settings that familiarize the individual with production requirements.

____1.4.4.7 Written, detailed training guides and curricula are available for all vocational training programs offered by the agency.

1.4.4.8 An agency that provides work training and employment opportunities by means of contract work procured from business or industry utilizes:

____1.4.4.8.1* time study procedures that are defined and consistently applied,

____1.4.4.8.2* competitive bidding practices, and

____1.4.4.8.3* written reimbursement agreements.

____1.4.4.9* The agency provides or obtains training (as defined in standard 1.4.3.2) for the development of work-related skills. Such skills include, but are not necessarily limited to:

____1.4.4.9.1* communication procedures;

____1.4.4.9.2* mobility requirements;

____1.4.4.9.3* interpersonal work relationships;

____1.4.4.9.4* job seeking skills (including finding a job and applying and interviewing for it);

____1.4.4.9.5* job-acceptable dress and hygiene;

____1.4.4.9.6* utilization of fringe benefits;

____1.4.4.9.7* understanding of grievance and separation procedures;

____1.4.4.9.8* adaptation to change in work or employment conditions and responsibilities; and

____1.4.4.9.9* understanding of employee organizations, such as labor unions.

____1.4.4.10* The agency provides or obtains job placement opportunities in a variety of work settings. Individual placements include, but are not necessarily limited to:

____1.4.4.10.1 work activity centers,

____1.4.4.10.2 sheltered employment centers,

____1.4.4.10.3 home employment,

____1.4.4.10.4 work stations in employment settings,

____1.4.4.10.5 competitive employment, and

____1.4.4.10.6 self-employment.

____1.4.4.11* The agency provides or obtains work-related follow-along services to assure that the individual adjusts to the work setting and has opportunity for job upgrading or reevaluation, so as to increase employment potential.

1.4.4.12 The agency assists employers by:

____1.4.4.12.1* familiarizing them with the agency's work training and employment programs,

____1.4.4.12.2* integrating the job-ready worker into the work force,

____1.4.4.12.3* training or retraining the worker in accordance with employment needs,

____1.4.4.12.4* helping workers to adjust to specific work environments,

____1.4.4.12.5* helping the employer to understand the special needs of the individual, and

____1.4.4.12.6* helping the employer to adapt the work environment to the special needs of the individual.

1.4.4.13 Individuals who are paid by the agency for work performed are provided employee benefits that include, but are not necessarily limited to:

____1.4.4.13.1 paid vacations, holidays, and sick leave;

____1.4.4.13.2 workman's compensation;

____1.4.4.13.3 health insurance;

____1.4.4.13.4 retirement; and

____1.4.4.13.5 social security (F.I.C.A.).

____1.4.4.14* The agency complies with applicable federal wage and hour laws. The agency has:

____1.4.4.14.1* appropriate and current wage and hour certificates,

____1.4.4.14.2* documentary evidence of each individual's production performance,

____1.4.4.14.3* documentary evidence of each individual's earning rate, and

____1.4.4.14.4* documentary evidence that individuals are paid on the basis of recorded production levels.

____1.4.4.15* The agency's work and employment programs meet applicable local, state, and federal safety requirements, particularly with reference to machinery, power equipment, including power hand tools, and storage for both raw materials and finished products.

1.4.5 Recreation and Leisure

Definitions

Recreation and leisure activities are elements of an individual's daily life in which participation may be planned, requested, or self-initiated to meet a basic need and to provide personal enjoyment. Leisure time services provide activities that make free time enjoyable and satisfying. Recreation services provide activities for developing skills, as well as for the enjoyment of free time. Therapeutic recreation activities are deliberate and purposeful interventions to enhance an individual's development by modifying the rate and direction of behavioral change.

Principles

Recreation services should provide activities designed to meet specific individual, personal, and therapeutic needs in self-expression, social interaction, and entertainment; to develop skills (including physical and motor skills) and interests leading to enjoyable and satisfying use of leisure time; and to improve socialization and increase interaction with other persons. The primary goal of recreation and leisure time activities should be to give individuals skills with which they can later exercise their own freedom in fulfilling leisure time pursuits in a normalizing manner. Recreation and leisure time activities should also provide coping experiences that encourage emotional growth.

A major objective of the recreation program should be the integration of developmentally disabled individuals into the recreation mainstream of the community. Consequently, agencies providing recreation and leisure time activities should utilize generic community recreation resources to the maximum possible extent. Without special attention, some developmentally disabled individuals may be excluded from community programs because they are not motivated or physically able to participate, or because they lack access to transportation. Programs should be designed to assure that all individuals will have opportunities to participate in recreation activities.

An individual program plan is not required for individuals participating only in leisure time activities.

Standards pertaining to all agencies

____1.4.5.1* If generic community recreation programs are unavailable to developmentally disabled individuals, the agency initiates activities to make such programs available within the service delivery system.

____1.4.5.1.1 The agency offers consultation and training services to generic agencies in developing and implementing recreation programs for developmentally disabled individuals.

____1.4.5.2* The agency keeps the population that it serves informed of various opportunities for recreation.

____1.4.5.3* The agency provides, obtains, or facilitates the provision of, activities for the enjoyable use of leisure time.

Standards pertaining only to agencies providing leisure time services

1.4.5.4 There is evidence that planning and organization of leisure time activities include:

____1.4.5.4.1 consideration of accessibility of, and transportation to, desired activities;

____1.4.5.4.2 consideration of any fees that are charged the participants;

____1.4.5.4.3* opportunities to participate with nondisabled people; and

____1.4.5.4.4 opportunities to participate with persons of both sexes.

Standards pertaining only to agencies providing recreation services

1.4.5.5 The agency provides recreation activities that are designed to:

____1.4.5.5.1* develop both group and individual leisure time skills;

____1.4.5.5.2* develop social interaction skills with both sexes, at all ages;

____1.4.5.5.3 develop and maintain physical and mental health; and

____1.4.5.5.4 group individuals according to their abilities and expressed wishes.

____1.4.5.6 To the maximum possible extent, recreation activities provided by the agency are available to developmentally disabled individuals who are served by other agencies, and to others who are not served by any direct program. Such recreation activities include, but are not necessarily limited to:

____1.4.5.6.1 daytime activities,

____1.4.5.6.2 after-school activities,

____1.4.5.6.3 after-work and evening activities,

____1.4.5.6.4 weekend activities,

____1.4.5.6.5 seasonal activities, and

____1.4.5.6.6 vacation activities.

1.4.5.7 **Recreation activities available to the individuals served are consistent with activities found in the community and include, as appropriate to the size and location of the agency and as adapted to the needs of the individuals:**

____1.4.5.7.1 excursions, outings, and other trips to familiarize individuals with community facilities;

____1.4.5.7.2 hobbies, collections, clubs, special interest and discussions groups, spectator activities, games, parties, and celebrations of special events;

____1.4.5.7.3 individual, dual, and team sports and lead-up activities; physical fitness and aquatic activities;

____1.4.5.7.4 outdoor and nature activities, including camping, wilderness camping, hiking, gardening, and winter activities;

____1.4.5.7.5 participation in a wide range of fine arts activities, from simple to complex, including music, drama, dance, rhythmics, and arts and crafts;

____1.4.5.7.6 service clubs and organizations; and

____1.4.5.7.7 opportunities to use leisure time in activities of the individual's own choosing.

Standards pertaining only to agencies providing therapeutic recreation programs

1.4.5.8 Therapeutic recreation programs include:

____1.4.5.8.1 assessments of the individual's abilities and performance level to determine the type of recreation activities that are appropriate;

____1.4.5.8.2 a specific set of objectives for each individual, as stated in the individual program plan; and

____1.4.5.8.3 careful selection of the method of presentation, in accordance with the individual's abilities.

1.4.6 Behavior Management

Definition

Behavior management refers to efforts to modify maladaptive or problem behaviors, and to replace them with behaviors that are adaptive and appropriate.

Principles

Developmentally disabled individuals often require services because they exhibit maladaptive behaviors, which are sometimes generated or aggravated by inappropriate management efforts. Programs to manage such behaviors must be directed to enhancing the development of the individual, in accordance with the developmental model and the principle of normalization. Consequently, such programs must emphasize the development of desirable and adaptive behaviors, rather than merely the elimination or suppression of undesirable ones. Reliance on punishment as the primary means of behavior control is unacceptable.

Behavior management, like all other aspects of the individual's program, must reflect evaluation and decision by the individual's interdisciplinary team, and be incorporated into the individual program plan. Behavior management programs must conform to the requirements for effective training or skill development. Methods utilizing punishment, restraint, other aversive techniques, or drugs, must represent the least restrictive effective alternatives, and programs should be designed to lead to less restrictive ways of managing, and ultimately to the elimination of, the behaviors for which they are employed. Special attention must be directed to assuring protection of the rights of the individual with whom such techniques are used.

Standards pertaining to all agencies

____1.4.6.1* The agency has written policies and procedures concerning behavior management. These policies and procedures are:

  ____1.4.6.1.1* directed to maximizing the growth and development of the individual by incorporating a hierarchy of available methods that emphasize positive approaches;

  ____1.4.6.1.2* available in each program area and living unit;

  ____1.4.6.1.3* available to individuals and their families; and

  ____1.4.6.1.4* developed with the participation, as appropriate, of individuals served.

____1.4.6.2* Corporal punishment and verbal abuse (shouting, screaming, swearing, name calling, or any other activity that would be damaging to an individual's self-respect) are prohibited by written policy and are not employed.

____1.4.6.3* Seclusion (defined as the placement of an individual alone, in a room or other area from which egress is prevented, not under observation as part of a systematic time-out program that meets all applicable standards) is not employed.

____1.4.6.4 When food is provided or withheld as part of a behavior management program, its effect on nutrition and dental status is considered.

  ____1.4.6.4.1 Foods that may be deleterious to health are not used as rewards unless it is documented that alternative rewards have been tried without success.

  ____1.4.6.4.2* Behavior management programs do not employ, or result in, denial of a nutritionally adequate diet.

____1.4.6.5* Individuals served do not discipline other individuals served, except as part of an organized self-government program that is conducted in accordance with written policy.

____1.4.6.6* The agency has a written policy that defines the use of behavior modification programs, the staff members who may authorize their use, and a mechanism for monitoring and controlling their use.

____1.4.6.7 Records are maintained of significant maladaptive behavior and of actions taken by parents and staff as a consequence of such behavior.

____1.4.6.7.1* When necessary, specialized therapeutic techniques to develop constructive, adaptive behaviors are provided or obtained by the agency for the individual and the family.

____1.4.6.8* When maladaptive or problem behaviors are to be modified, the individual's program plan includes provisions to teach the individual the circumstances under which the behaviors can be exhibited appropriately, to channel the behaviors into similar but appropriate expressions, or to replace the behaviors with behaviors that are adaptive and appropriate.

1.4.6.8.1 Each plan to modify maladaptive behaviors specifies:

____1.4.6.8.1.1* the behavioral objectives of the program,

____1.4.6.8.1.2* the method to be used,

____1.4.6.8.1.3* the schedule for use of the method,

____1.4.6.8.1.4* the person responsible for the program, and

____1.4.6.8.1.5* the data to be collected to assess progress toward the objectives.

____1.4.6.8.2* Whenever restraint, behavior-modifying drugs, or behavior modification techniques involving the use of time-out devices or aversive stimuli are employed to eliminate maladaptive or problem behaviors, the individual's record documents the fact that less restrictive methods of modifying or replacing the behavior have been systematically tried and have been demonstrated to be ineffective.

____1.4.6.9* Except when used as a time-out device, in accordance with applicable standards, physical restraint is employed only when absolutely necessary to protect the individual from injury to him or herself or to others, and restraint is not employed as punishment, for the convenience of staff, or as a substitute for program.

____1.4.6.9.1* Physical restraint is used only as an integral part of an individual program plan that is designed by an interdisciplinary team to lead to a less restrictive way of managing, and ultimately to the elimination of, the behavior for which the restraint is applied.

1.4.6.9.1.1 Each program plan utilizing restraint specifies:

____1.4.6.9.1.1.1* the behavior to be eliminated,

____1.4.6.9.1.1.2* the method to be used,

____1.4.6.9.1.1.3* the schedule for use of the method,

____1.4.6.9.1.1.4* the person responsible for the program, and

____1.4.6.9.1.1.5* the data to be collected to assess progress toward the objectives.

1.4.6.9.1.2 Each program plan utilizing restraint is reviewed and approved prior to implementation:

____1.4.6.9.1.2.1* by the agency's behavior management committee, and

____1.4.6.9.1.2.2* by the agency's human rights committee.

____1.4.6.9.1.3* The individual's record documents all periods of restraint, with justification and authorization for each.

____1.4.6.9.2* The agency has a written policy that defines the uses of restraint, the staff members who may authorize its use, and a mechanism for monitoring and controlling its use.

____1.4.6.9.2.1* Orders for restraint are not in force for longer than 12 hours.

____1.4.6.9.2.1.1* Standing or PRN orders for restraint are not used.

____1.4.6.9.2.2* An individual placed in restraint is checked at least every thirty minutes by staff trained in the use of restraints, and a record of such checks is kept.

____1.4.6.9.2.3* Restraints are designed and used so as not to cause physical injury to the individual, and so as to cause the least possible discomfort.

____1.4.6.9.2.4* Opportunity for motion and exercise is provided for a period of not less than ten minutes during each two hours in which restraint is employed, and a record of such periods is kept.

____1.4.6.9.2.5* Totally enclosed cribs are considered to be restraints, and their use is governed by the agency's written policy concerning restraint and by the standards concerning restraint.

____1.4.6.9.2.5.1* Barred enclosures other than cribs (such as play pens) are not more than three feet in height and do not have tops.

____1.4.6.10* Medication is not used as punishment, for the convenience of staff, as a substitute for a program, or in quantities that interfere with an individual's developmental program.

____1.4.6.10.1* Drugs used for behavior management are utilized only as an integral part of an individual program plan designed by an interdisciplinary team to lead to a less restrictive way of managing, and ultimately to the elimination of, the behaviors for which the drugs are employed. Each program plan utilizing drugs for behavior management:

____1.4.6.10.1.1* specifies the behavior to be modified, a time-limited (no more than 30 days) prescription by a fully licensed physician, and the data to be collected to assess progress toward the treatment objective;

____1.4.6.10.1.2* documents the fact that any potentially harmful effects of the drugs employed have been carefully weighed against the harmful effects of the behavior for which the drugs are given, and that the harmful effects of the behavior clearly outweigh the potentially harmful effects of the drugs;

____1.4.6.10.1.3 includes explicit provision for gradual diminishing of dosage and ultimate discontinuation of the drug; and

1.4.6.10.1.4 is reviewed and approved prior to implementation by:

____1.4.6.10.1.4.1* the agency's behavior management committee, and

____1.4.6.10.1.4.2* the agency's human rights committee.

____1.4.6.10.2 The individual's record contains written authorization for the use of behavior modifying drugs, signed by the individual, if competent, or by the individual's parents or guardian.

____1.4.6.10.2.1 Individuals of legal age who are mentally competent to understand the purpose and nature of the plan participate in developing the plan for the use of behavior modifying drugs, give their permission for such use, and are allowed to discontinue such use under medical supervision at any time.

____1.4.6.10.2.2 The parents and legal guardians of an individual for whom the use of behavior modifying drugs is proposed are informed, both orally (by conference, if possible) and in writing, of the drugs to be used. This information:

____1.4.6.10.2.2.1 conveys in a simple, nontechnical, and comprehensible manner the drugs to be used, their expected benefits, and their possible hazards; and

____1.4.6.10.2.2.2 is given in such form as is necessary to communicate the information effectively (notice to persons having perceptual or language impediments is given by a method or in a language that is comprehensible to them).

____1.4.6.10.2.3 Individuals or parents and guardians have the right to refuse the outlined plan for use of behavior modifying drugs, in which event the agency has the right to appeal the matter to a court of competent jurisdiction for adjudication.

1.4.6.11 Each behavior modification program that involves the use of aversive conditioning or time-out devices is:

1.4.6.11.1 reviewed and approved prior to implementation:

____1.4.6.11.1.1* by the agency's behavior management committee, and

____1.4.6.11.1.2* by the agency's human rights committee;

____1.4.6.11.2* conducted only with the written consent of the affected individual and/or the individual's family, as appropriate; and

____1.4.6.11.3* described in the individual's program plan.

____1.4.6.11.4* When a time-out device is employed, the individual's record documents the fact that the situation from which the individual is removed for time-out provides consistent and positive reinforcement of desired, adaptive behaviors.

____1.4.6.11.5* Removal from a situation for time-out purposes occurs only during the conditioning program and only under the direct observation of the persons conducting the program.

____1.4.6.11.5.1* Removal from a situation for time-out purposes is for not more than one hour, except in extraordinary instances (ordinarily occurring only in the beginning of a time-out program) that are personally approved at the time of occurrence by a member of the individual's interdisciplinary team.

____1.4.6.11.6* Restraints employed as time-out devices are applied only during conditioning sessions and only in the presence of the persons conducting the program.

____1.4.6.11.6.1* Restraints employed as time-out devices are applied for not more than fifteen minutes, except in extraordinary instances (ordinarily occurring only in the beginning of a time-out program) that are personally approved at the time of occurrence by a member of the individual's interdisciplinary team.

____1.4.6.11.7* Key locks are not employed on rooms in which individuals are confined for time-out.

____1.4.6.11.8* Aversive conditioning is used only in those extreme, last-resort situations in which withholding it would be contrary to the best interests of the individual because his or her behavior is dangerous to him or herself or to other persons and is extremely detrimental to his or her development, and because the individual's failure to respond to positive reinforcement procedures has been documented in his or her record.

1.5 Individual Program Coordination

Definition

Individual program coordination is the process by which responsibility for implementation of the individual's program plan is established. The process includes providing support, obtaining direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the individual.

Principles

Each agency providing services to an individual should assign a person to coordinate the agency's activities in implementing the individual's program plan. This person should be responsible for implementing the agency's role in the individual program plan and for assuring that all relevant staff, as well as the individual and, when appropriate, the individual's family, focus their efforts on attaining the objectives specified in the plan. The individual program coordination process should be terminated only when services to the individual have been terminated.

When two or more agencies provide services to an individual, an agency should be designated to be responsible for coordinating the individual's overall program plan.

Standards pertaining to all agencies

____1.5.1* Each individual served by the agency is assigned a person who is responsible for coordinating the agency's activities in implementing the individual's program plan.

____1.5.1.1* The person responsible for coordinating the individual's program is identified to the individual, the individual's family, and the appropriate staff members.

____1.5.1.2 The agency's written procedures provide for opportunities for the individual or the individual's family to request a change of the person responsible for coordinating the individual's program.

____1.5.1.2.1 Procedures for requesting change of the person responsible for coordinating the individual's program are made known to all parties concerned.

1.5.2 The person responsible for coordinating the individual's program:

____1.5.2.1* attends to the total spectrum of the individual's needs, including but not necessarily limited to, housing, family relationships, social activities, education, finance, employment, health (including special health needs), recreation, mobility, protective services, and records;

____1.5.2.2* locates, obtains, and coordinates services outside and inside the agency, as needed by the individual;

____1.5.2.3 secures relevant data from other agencies providing service, to keep the individual program plan up to date;

____1.5.2.4 provides documentation concerning coordination of the individual program plan;

____1.5.2.5 monitors the operation of the services that are provided the individual in accordance with the individual program plan;

____1.5.2.6 intervenes when necessary to assure implementation of the plan;

____1.5.2.7 requests, when necessary, review of the individual program plan by the individual's interdisciplinary team; and

____1.5.2.8* facilitates the transfer of the individual to another service or agency, when such transfer is appropriate to meet the individual's needs.

____1.5.3* When two or more agencies provide services to an individual, an agency is designated to be responsible for coordinating the individual's overall individual program plan.

1.6 Programming Records

(See also sections 3.1 and 4.10.4)

Definition

Programming records are those records that are essential for effective individual program planning and implementation.

Principles

In order that the shared deliberations and decisions of the interdisciplinary team result in the design and implementation of a totally integrated plan, rather than in fragmented, isolated, or independent efforts, the individual program planning and implementation process must be documented. The establishment and maintenance of a functional record keeping system is therefore an essential activity of each service agency. The system should provide for the compilation of data that will be useful in developing an effective individual program plan and in reviewing and revising the plan on the basis of the individual's response to it. Consequently, the system must furnish data concerning the individual's progress toward the objectives specified in the individual program plan and concerning services provided and actions taken in accordance with the plan. Because persons from a variety of professional backgrounds must use the individual's record in order to implement the individual program plan, entries in the record must be written in such a way as to convey meaningful information to all who are involved with the individual. The record should include objective data and reports of observable behaviors, rather than inferences, assumptions, and interpretations that may not be defensible.

While the individual's main or "unit" record must contain a statement of the overall objectives determined by the individual's interdisciplinary team, as incorporated in the individual program plan, it need not contain all the detailed information concerning each service or program that is subsequently designed and provided to achieve those objectives. Such information must, however, be available where the program is conducted (that is, in the living unit or other program area). All activities pertaining to the individual must be clearly documented so that their relationship to the overall individual program plan is evident, and so that consistent implementation of the plan is assured.

The standards are not intended to require record keeping for its own sake. The recording requirements are those necessary to assure effective individual program planning and implementation, and these requirements may be met by records that are concise but precise. Functional records that meet these requirements assist in protecting the legal rights of the individual, the agency, and the agency's staff. They also provide a basis for review and evaluation of the agency's programs, and furnish data that are useful for research and education, provided, of course, that the requirements concerning the confidentiality of records and the right of access to them are observed.

Standards pertaining to all agencies

____1.6.1* A chronologically continuous record is maintained for each individual served. The individual's record:

  ____1.6.1.1* documents an evaluation that identifies the individual's specific needs;

  ____1.6.1.2* specifies the individual program plan devised to meet the individual's identified needs;

____1.6.1.3* documents observations of the individual's response to the program;

____1.6.1.4* documents review and modification of the individual program plan in the light of the individual's response to it;

____1.6.1.5* provides a means of communication among all persons contributing to the individual's program;

____1.6.1.6* documents protection of the legal rights of the individual, the agency, and the staff, by recording actions that significantly affect the legal rights of the individual, as defined by state and federal law and regulations;

____1.6.1.7* furnishes a basis for review, study, and evaluation of the overall programs provided by the agency; and

____1.6.1.8 provides data for use in research and education.

____1.6.2* Results, recommendations, and actions of the interdisciplinary assessment process are recorded for use in the development and implementation of the individual program plan.

1.6.3 Within three months after entry or one month after admission or enrollment, whichever comes first, the following items are entered in the individual's record:

____1.6.3.1* a report of a review and updating, as necessary, of the entry, admission, or enrollment information; and

____1.6.3.2* an individual program plan designed by an interdisciplinary team.

1.6.4 Record entries during the period of service to the individual include:

____1.6.4.1* date(s) of enrollment(s);

____1.6.4.2* records of services provided and attendance;

____1.6.4.3* reports of accidents, seizures, illnesses, and treatments thereof, and immunizations;

____1.6.4.4* records of significant behavior incidents;

____1.6.4.5* records of agency contacts with the individual's family; and

____1.6.4.6 pertinent correspondence.

1.6.5 All entries in the individual's record are:

____1.6.5.1* legible;

____1.6.5.2* dated;

____1.6.5.3* authenticated by the signature and identification of the person making the entry; and

____1.6.5.4 to the extent possible, written in nontechnical terms.

____1.6.6* Where particular professional services require the maintenance of separate records, a summary of the information contained therein is entered in the individual's main or "unit" record.

____1.6.7* Where a centralized record keeping system is used, appropriate records are also available in program and living units.

Section 2
Alternative Living Arrangements

Definition

An alternative living arrangement is a place of residence that substitutes for the individual's own home or for the home of the individual's family, and that affords living experiences appropriate to the individual's functioning level.

Principles

The parental home is usually the most normalizing and appropriate environment for children and adolescents. Adults ordinarily seek to establish their own homes as they attain economic sufficiency and dependency needs decrease. Primary emphasis should therefore be placed on providing services, both in and out of the home, that will enable developmentally disabled individuals to remain with their families or in their own homes, as appropriate. When it has been carefully determined that an individual can or should no longer remain with the family or live independently, assistance should be given to the individual and/or the family in planning for and securing appropriate alternative living arrangements.

A broad range of living arrangements must be available to meet the needs of developmentally disabled individuals and to facilitate their integration into community life. Alternative living arrangements that are appropriate to the support and supervision required by the individuals being served should be developed. Such arrangements should provide environments that are conducive to the development of adaptive behaviors and self-help and independent living skills, and that facilitate, to the greatest possible extent, continuity with culturally normative living patterns. Consequently, alternative living arrangements should be situated within the community; have interior and exterior features that are comparable to those of other facilities in the neighborhood; be separate from sites where other activities, such as education or work, occur; and be accessible to needed community resources. The range of alternative living arrangements should include both generic and specialized arrangements; in-home services, such as homemaker and sitter/companion services; surrogate family homes; short-term, out-of-home services; and both congregate and individual living arrangements, with staff supervision and availability appropriate to the needs of the individuals being served. There must be provision to facilitate movement of individuals to the least restrictive environments appropriate to their needs.

Agencies that provide or obtain alternative living arrangements should assure that individuals secure needed resources and services. Assessments of the developmental progress of individuals should be used to determine current and projected needs for alternative living arrangements. Living-arrangements staff must be involved in planning and implementing programs for the individuals being served, and such staff should receive training that will increase their ability to provide effective, development-enhancing services to developmentally disabled individuals.

2.1 Attention to Normalization and Use of Least Restrictive Alternatives

Definitions

Normalization requires making available to developmentally disabled individuals patterns and conditions of everyday life that are as similar as possible to those of the mainstream of society, thereby enabling such individuals to enjoy a manner of living that is as close as possible to that considered to be normal in the community. The related principle of using the least restrictive alternative requires that any intervention be the least intrusive into, and least disruptive of, the individual's life, and represent the least departure from normal patterns of living, that can be effective in meeting the individual's developmental needs.

Principles

Because most alternative living arrangements involve some departure from culturally normative practices, special attention to implementation of normalization and use of the least restrictive alternatives must underlie all such arrangements. Normalization includes providing a normal rhythm of life; normal rhythm of the day, with respect to getting up, getting dressed, participating in play and work activities, eating meals, retiring, and so forth; normal rhythm of the week, including differentiation of daily activities and schedules; and normal rhythm of the year, including observing holidays, days with personal significance, and vacations.

Standards pertaining to all agencies

____2.1.1 The agency provides or obtains services or equipment needed to enable individuals to remain in their own or parental homes, as appropriate.

____2.1.1.1 If the agency does not provide homemaker services, it identifies sources for obtaining such services.

____2.1.1.2 If the agency does not provide sitter/companion services, it identifies sources for obtaining such services.

____2.1.1.3 If the agency does not provide temporary-assistance living arrangements, it identifies sources for obtaining such arrangements.

____2.1.1.4 When it is necessary for an individual to be placed out of his or her own or parental home, the agency documents the efforts that were made to enable the individual to remain with his or her family or in independent living, and documents that continued placement with the family or in independent living is not in the individual's best interest.

____2.1.2 The agency provides assistance to the individual and/or the individual's family in planning for and securing living arrangements that are appropriate to the individual's functioning level.

____2.1.3 The agency documents activities leading to the development of full time, part time, and temporary living arrangements, with appropriate degrees of supervision, and related in-home services. Such arrangements include, but are not necessarily limited to:

  ____2.1.3.1 twenty-four hour care,

  ____2.1.3.2 night care,

  ____2.1.3.3 less-than-seven-days-a-week services,

  ____2.1.3.4 temporary assistance,

  ____2.1.3.5 supervision and support for groups of individuals,

  ____2.1.3.6 staff supervision for individuals,

  ____2.1.3.7 surrogate family care,

  ____2.1.3.8 semi-independent living arrangements,

  ____2.1.3.9 homemaker services,

  ____2.1.3.10 chore services, and

  ____2.1.3.11 sitter/companion services.

  ____2.1.3.12 When specialized, rather than generic, living arrangements are necessary, the agency assists in developing specialized living arrangements that are adapted to the needs of the individuals to be served.

Standards pertaining only to agencies providing alternative living arrangements services

____2.1.4 The agency implements the principle of using the least restrictive alternatives to meet the needs of individuals served, by making every attempt to move individuals from more to less structured living, larger to smaller facilities, larger living units to smaller living units, group to individual residence, dependent to independent living, and segregated to integrated living.

____2.1.5 The agency has a written plan for the development and implementation of alternative living arrangements. The plan includes, but is not necessarily limited to:

  ____2.1.5.1 determination of numbers of individuals needing to be served, by age and degree of handicap;

  ____2.1.5.2 types of living arrangements needed, according to the individuals' needs for supervision;

  ____2.1.5.3 plans for grouping individuals in accordance with individual needs;

  ____2.1.5.4 staffing and supportive services required;

  ____2.1.5.5 funding sources to be utilized for the support of living arrangements;

  ____2.1.5.6 occupancy analysis of existing alternative living arrangements to determine the need for additional arrangements; and

  ____2.1.5.7 schedules for developing additional alternative living arrangements.

____2.1.6* Living arrangements utilized by the agency provide access to other community services and activities for the individuals served.

____2.1.6.1* There is a formal arrangement for providing qualified and adequate dental, medical, and pharmacy services, including emergency services, on a 24-hour, seven-days-a-week basis.

____2.1.7* Living arrangements used by the agency are physically integrated within the community.

____2.1.7.1 Residences utilized by the agency have interior and exterior features that are comparable to those of other residences in the neighborhood.

____2.1.8 An outdoor recreation area is readily accessible from each residence.

____2.1.9* It is documented that living arrangements utilized for placement comply with applicable fire, health, and sanitation standards.

____2.1.9.1* Each habitable room has direct outside ventilation by means of windows, louvers, air conditioning, or mechanical ventilation horizontally and vertically.

____2.1.9.2* Each habitable room has at least one window.

2.1.10 Bedrooms:

____2.1.10.1* are outside rooms, and

____2.1.10.2* accommodate from one to four residents.

2.1.10.3 Each resident is provided with:

____2.1.10.3.1* a separate bed of proper size and height for his or her convenience;

____2.1.10.3.2* a clean, comfortable mattress;

____2.1.10.3.3* bedding appropriate for weather and climate;

____2.1.10.3.4* a comfortable pillow, unless contraindicated by the resident's decision or for health reasons;

____2.1.10.3.5* appropriate individual furniture, such as a chest of drawers and a table or desk; and

____2.1.10.3.6* a place for personal possessions and, when needed, for individually prescribed prosthetic and mobility equipment.

____2.1.11* The "rhythm of life" in the residence is in accordance with the cultural norm for the residents' non-disabled age peers, unless a departure from this rhythm is justified on the basis of maximizing the residents' human qualities.

____2.1.11.1* Residents are allowed free access to all living areas within the residence, with due regard for the privacy and personal possessions of others.

____2.1.11.2* Each resident has access to a quiet, private area to which he or she can go when not engaged in structured activities.

____2.1.11.3 Residents are not kept in bed, or in their bedroom areas, during normal waking hours, except as specified in their individual program plans.

____2.1.11.3.1* Multiply handicapped and nonambulatory residents have planned daily activity and exercise periods.

____2.1.11.4* All residents have planned periods out of doors on a year-round basis, unless contraindicated in their individual program plans.

____2.1.11.4.1* Orders prescribing bed rest or prohibiting residents from being taken out-of-doors are reviewed by a physician at least every three days, unless otherwise specified in their individual program plans.

2.1.11.5 Except as contraindicated for individual residents by their individual program plans, residents have freedom of movement:

____2.1.11.5.1* on the premises of the residence or residential facility, and

____2.1.11.5.2* off the premises of the residence or residential facility.

2.1.11.6 Except as denied individual residents by action of their interdisciplinary teams, for cause, residents:

____2.1.11.6.1* have access to telephones for incoming and local outgoing calls;

____2.1.11.6.2* have access to telephones (which may be pay telephones) for outgoing long distance calls;

____2.1.11.6.3* open their own mail and packages, generally without direct surveillance; and

____2.1.11.6.4* do not have their outgoing mail read by staff, unless requested by the resident.

____2.1.11.7* Individuals participate within their own living areas in household responsibilities appropriate to their developmental needs and abilities.

____2.1.11.8* In accordance with their developmental levels, allowances or opportunities to earn money are available to residents.

____2.1.11.9* Residents are encouraged to have personal possessions, such as toys, books, pictures, games, radios, arts and crafts materials, religious articles, toiletries, jewelry, and letters.

____2.1.11.9.1* Residents have individual toilet articles that are appropriately available to them.

____2.1.11.9.2 Residents are encouraged to decorate their bedrooms with such articles as pictures, flowers, or artwork.

____2.1.11.10* Residents' birthdays and other special events are individually observed.

____2.1.12* At least three daily meals, served at regular times, are provided or obtained for individuals served in residential programs.

____2.1.12.1* Meal times are comparable to those normally obtaining in the community.

____2.1.12.2 There are not less than ten hours between breakfast and the evening meal of the same day.

____2.1.12.3 Between-meal and before-bedtime snacks are provided, in keeping with the individual's total daily needs.

____2.1.12.4* All individuals, including those who are mobile nonambulatory, eat or are fed in dining rooms, except where contraindicated for health reasons, or by decision of the individual's interdisciplinary team.

____2.1.12.4.1* All who can and will eat at a table, including individuals in wheelchairs, do so.

____2.1.12.5 For individuals who are unable to get to dining areas, food service practices permit and encourage maximum self-help, and promote social interaction and enjoyable experiences.

____2.1.13* Each resident has an adequate allowance of neat, clean, fashionable, and seasonable clothing.

____2.1.13.1* Residents have and wear their own clothing, which is, when necessary, properly (inconspicuously) marked with their names.

____2.1.13.2* Nonambulatory residents are dressed daily in their own clothing, including shoes, unless contraindicated in written medical orders.

____2.1.13.3 Clothing is kept in good repair.

____2.1.13.4* Storage space to which the resident has access is provided for the resident's clothing.

____2.1.13.4.1 Ample and accessible closet and drawer space is provided for each resident.

____2.1.14* Normal, individualized haircutting and styling, by trained persons, are available to all residents; residents are encouraged to use these services; and those residents whose functioning level so requires are regularly scheduled for such services.

____2.1.15 Mirrors are provided in residences, including mirrors that are usable by residents in wheelchairs.

____2.1.16* Residents who require assistance in cutting their toenails and fingernails, and in shaving, are regularly scheduled to receive such assistance from trained persons.

____2.1.17 Each resident has a shower or tub bath daily, unless contraindicated.

2.1.17.1 Residents bathe or are bathed:

____2.1.17.1.1* at the most independent level possible, and

____2.1.17.1.2* with due regard for privacy.

____2.1.17.2 Appropriate soap is used for bathing, unless otherwise prescribed.

____2.1.18* Individual washcloths and towels are used.

____2.1.19* Residents brush their teeth, or their teeth are brushed, daily with an effective dentifrice.

____2.1.19.1* Individual toothbrushes are properly identified, used, and stored.

____2.1.19.2 Dental care practices encourage the use of newer dental equipment, such as electric toothbrushes and water picks, as prescribed.

____2.1.20 All prosthetic and orthotic devices are clearly, permanently, and appropriately labeled with the individual's name.

2.2 Homemaker and Sitter/Companion Services

Definitions

Homemaker and sitter/companion services are in-home services provided to enable developmentally disabled individuals to remain with their families or in their own homes. Homemaker services include services which involve caring for the family in the home during periods of need or crisis, and teaching family members techniques of home management. Sitter/companion services provide in-home care of, or assistance to, a disabled individual.

Principle

Since primary emphasis should be placed on providing services that will enable developmentally disabled individuals to remain with their families or in their own homes, in-home services should be provided or obtained whenever needed.

Standards pertaining only to agencies providing homemaker services

2.2.1.1 The agency's homemaker services are available when needed:

____2.2.1.1.1* to families with a disabled individual living at home, and

____2.2.1.1.2* to disabled adults living in their own homes.

____2.2.1.2* The agency has a written plan for recruiting, selecting, training, and evaluating persons who provide homemaker services.

____2.2.1.3* The homemaker assists with, and teaches appropriate techniques of, home management, including health care, meal planning, marketing, budgeting, and housekeeping.

____2.2.1.4 The homemaker's home management skills are sufficient to meet a variety of family emergencies, including relief in a crisis.

____2.2.1.5 In nonemergency situations, evaluation of the family's needs is made prior to the provision of homemaker services and continues after the homemaker is in the home.

____2.2.1.6 The homemaker is informed of the family situation prior to entering the home.

____2.2.1.7 The homemaker is prepared to assist with the training program of the disabled individual, so that the individual may remain in the home.

Standards pertaining only to agencies providing sitter/companion services

____2.2.2.1 The agency's sitter/companion services are available for the length of time needed.

____2.2.2.2 The agency has a written plan for recruiting, selecting, training, and evaluating personnel who provide sitter/companion services.

2.3 Temporary-Assistance Living Arrangements

Definition

Temporary-assistance living arrangements (or respite care services) are those components of the alternative living arrangement services network that provide primarily short-term, in- or out-of-the-home care of a developmentally disabled individual for the temporary relief of the individual or the family, or in times of crisis.

Principle

Since primary emphasis should be placed on providing services, both in and out of the home, that will enable developmentally disabled individuals to remain with their families (when that is appropriate for them), temporary-assistance living arrangements should be provided whenever necessary to obviate the need for placement outside the home, or to keep the duration of such placement to a minimum.

Since thirty days is allowed for development of an initial individual program plan, an individual program plan is not required for an individual receiving respite care for a period not exceeding thirty days.

Standards pertaining only to agencies providing temporary-assistance living arrangements services

____2.3.1* The agency has a written plan for recruiting, selecting, training, and evaluating persons or agencies that provide temporary-assistance living services.

  ____2.3.1.1 The agency has written criteria for identifying persons or agencies capable of providing temporary-assistance living services.

  ____2.3.1.2 Persons or agencies providing temporary residential assistance have evidence of meeting appropriate licensing requirements.

____2.3.2 The agency has written policies and procedures concerning temporary-assistance living arrangements. Such policies and procedures include, but are not necessarily limited to:

  ____2.3.2.1 criteria governing admittance to temporary residential placements;

  ____2.3.2.2 entry procedures for families and agencies requesting the service;

  ____2.3.2.3 criteria for length of stay; and

  ____2.3.2.4 guidelines governing termination of stay before, or extension of stay beyond, that initially stipulated for the individual.

____2.3.3 The agency implements activities that assure continuity with the normal living patterns of the individuals served.

  ____2.3.3.1 Temporary-assistance living arrangements provide for utilization of community resources as appropriate to individual needs.

2.4 Surrogate Family Services

Definition

Surrogate family services (including foster family services) provide individuals with substitute family homes under contractual arrangements between surrogate families and the placing agency.

Principle

Since the parental home is usually the most normalizing and appropriate environment for children and adolescents, and may be the most appropriate environment for older individuals, and since surrogate family homes provide an alternative living environment that is most like that of the natural parental home, the suitability and possibility of utilizing surrogate family services should always be explored when placement of developmentally disabled individuals outside their parental or own homes becomes necessary.

Standards pertaining only to agencies providing surrogate family services

____2.4.1* The agency has a written plan for recruiting, screening, selecting, and evaluating surrogate family homes.

____2.4.1.1* Surrogate family homes are licensed or otherwise approved by the appropriate state or local authority.

____2.4.1.2* Surrogate family homes are monitored and supervised by the agency or an appropriate authority at least quarterly.

____2.4.1.3* Surrogate family homes are evaluated at least annually by the agency or an appropriate authority.

____2.4.2* The agency provides or obtains orientation and training programs for surrogate families prior to placing individuals in their homes. Such training programs include, as appropriate, but are not necessarily limited to:

____2.4.2.1 orientation to agency philosophy, policies, procedures, and services;

____2.4.2.2 causes and prevention of developmental disabilities;

____2.4.2.3 human and legal rights;

____2.4.2.4 architectural barriers;

____2.4.2.5 normalization;

____2.4.2.6 confidentiality;

____2.4.2.7 health and nutrition;

____2.4.2.8 first aid;

____2.4.2.9 management of seizure disorders;

____2.4.2.10 methods of assisting individuals with physical disabilities;

____2.4.2.11 medication;

____2.4.2.12 methods of training residents;

____2.4.2.13 measuring individual development;

____2.4.2.14 developing goals and objectives for individuals served;

____2.4.2.15 recreation, including physical activities; and

____2.4.2.16 surrogate family legal liabilities and responsibilities.

____2.4.3* The agency provides surrogate families with an ongoing training program designed to enhance previously acquired skills.

2.4.4 In placing individuals in surrogate family homes, the agency utilizes identifiable procedures that specifically consider:

____2.4.4.1 the community resources needed by the individual,

____2.4.4.2 the cultural backgrounds of the surrogate family and the individual, and

____2.4.4.3 the relationships of surrogate family members to the individual.

____2.4.5* The surrogate family maintains appropriate records. Such records include, but are not necessarily limited to:

____2.4.5.1 contacts with the individual's natural family;

____2.4.5.2 significant behaviors of, or incidents relating to, the individual;

____2.4.5.3 health-related needs and services provided; and

____2.4.5.4 financial transactions concerning the individual.

____2.4.6 The budgeting and disposition of the financial resources or other personal property of the individual follow guidelines established by the placing agency.

____2.4.6.1* The agency monitors the record of financial transactions conducted by the surrogate family for the benefit of the individual.

____2.4.7* The agency has a written contract with each surrogate family. Each contract includes, but is not necessarily limited to, specification of:

____2.4.7.1 the roles and responsibilities of the agency, the individual's family, and the surrogate family; and

____2.4.7.2 the financial payment to be provided to the surrogate family.

____2.4.8 The agency identifies the outcomes of surrogate family services, as well as the reasons for continuing or terminating such services.

____2.4.8.1 Findings concerning surrogate family placement failures, and consequent plans for remediation, are recorded.

2.5 Congregate Living Services

Definition

Congregate living services encompass all alternative living arrangements that serve individuals in groups, from small group homes providing domiciliary services and personal-social assistance to relatively independent residents who may be engaged in sheltered or competitive employment, to institutions providing intensive, 24-hour programming to residents with multiple needs and multifarious and severe handicaps.

Principles

The primary focus of all programs for developmentally disabled individuals must be on facilitating the development of such individuals. Consequently, each congregate living program must provide at least domiciliary services that are designed to enhance the development of each resident in conjunction with other services that are provided in accordance with an individual program plan. The agency providing the residential services may or may not have responsibility for developing and maintaining the individual program plans of the residents served. However, some agency must have that responsibility, and its locus must be identified. In any event, the agency providing residential services must participate in developing, implementing, reviewing, and revising the plan, in accordance with its role in providing services for the individual, as specified in the plan.

The scope and intensity of the services, in addition to domiciliary services, that must be provided by a residential program vary according to the identified needs of its residents, and according to the program's specified role in the individual program plans designed to meet those needs. The program's responsibility for providing services other than domiciliary may be fulfilled by providing such services or by obtaining them from other sources. The program need provide only development-enhancing domiciliary services.

2.5.1 The Congregate Living Environment

Definition

The congregate living environment includes those physical, social, and psychological features necessary to implement normalization while, at the same time, providing the conditions necessary to effectively train individuals in adaptive behaviors and independent-living skills.

Principles

The congregate living environment must facilitate both the implementation of normalization and the provision of effective training. Departures from a normal environment must be justified on the basis of maximizing the functioning and enhancing the development of the residents served.

Normalization requires that nonambulatory and other physically or multiply handicapped individuals not be segregated solely on the basis of their handicaps. Specialized programs, in specialized environments, may be provided to individuals with special handicaps, if such programs are demonstrably directed to enhancing the development of the individuals that are being served, have as their objective the return of those individuals to nonspecialized environments, and provide for as much interaction with nonhandicapped individuals as possible.

Standards pertaining only to agencies providing congregate living services

____2.5.1.1* The grouping of program and residence units is based upon a rational plan to meet the needs of the individuals served.

____2.5.1.1.1* Living unit components or groupings are small enough to assure the development of meaningful interpersonal relationships among residents and between residents and staff.

____2.5.1.1.1.1 Each resident-living unit (self-contained unit including sleeping, dining, and activity areas) accommodates not more than 16 residents.

____2.5.1.1.1.2 To maximize development, residents are grouped within each living unit into program groups of not more than eight.

____2.5.1.1.2 Residential units or complexes house both male and female residents to the extent that this is culturally normative.

____2.5.1.1.3* Residents who are mobile-nonambulatory or multiply handicapped are integrated with peers of comparable social and intellectual development, and are not segregated within the facility on the basis of their handicaps, unless contraindicated by the specific program needs of the particular residents being served.

____2.5.1.1.4* Residents of grossly different ages, developmental levels, and social needs are not housed in close physical or social proximity, unless such housing is planned to promote the development of all those housed together.

____2.5.1.2* Living unit activities are coordinated with recreation, educational, and habilitative activities in which residents engage outside the living unit, unless contraindicated by the specific program needs of the residents being served.

2.5.1.3 The design, construction, and furnishing of each living unit is:

____2.5.1.3.1* appropriate to the program,

____2.5.1.3.2 flexible enough to accommodate variations in program to meet changing needs of residents, and

____2.5.1.3.3 such as to minimize noise and permit communication at normal conversation levels.

____2.5.1.3.4* The interior design of each living unit simulates the functional arrangements of a home to encourage a personalized atmosphere for small groups of residents, unless it has been demonstrated that another arrangement is more effective in maximizing the functioning of the specific residents being served.

____2.5.1.3.5 Each living unit provides a total of at least 80 square feet of living, dining, or activity space for each resident.

____2.5.1.3.6 Living, dining, and activity space is arranged to permit residents to participate in various kinds of activities, both in groups and alone.

____2.5.1.3.7* Furniture and furnishings are safe, appropriate, comfortable, and home-like.

2.5.1.3.8 Bedrooms:

____2.5.1.3.8.1* are on or above street grade level; and

____2.5.1.3.8.2* provide at least 60 square feet per resident in multiple sleeping rooms, and at least 80 square feet in single rooms, with additional space provided for bedside assistance and use of wheelchairs, where needed.

____2.5.1.3.8.3 Partitions separating bedrooms provide visual privacy, and preferably extend from floor to ceiling.

____2.5.1.3.8.4 Doors to bedrooms do not have vision panels, except where indicated by the specific program needs of the individuals being served.

____2.5.1.3.9* Toilet areas, clothes closets, and other facilities are located and equipped to facilitate training toward maximum self-help by residents, including serverely and profoundly handicapped residents.

2.5.1.3.10 Unless contraindicated by the specific program needs of the particular residents being served:

____2.5.1.3.10.1* toilets, showers, bathtubs, and lavatories approximate normal configurations found in homes; and

____2.5.1.3.10.2* toilets, bathtubs, and showers provide for individual privacy.

2.5.1.3.11 Each living unit has:

____2.5.1.3.11.1 at least one toilet of appropriate size for every six residents,

____2.5.1.3.11.2 at least one lavatory for every six residents,

____2.5.1.3.11.3 at least one tub or shower for every eight residents, and

____2.5.1.3.11.4 individual racks or other drying space for washcloths and towels.

____2.5.1.3.12 Each living unit housing children has at least one window low enough so that a child can see outside while engaged in normal daytime activities.

____2.5.1.3.13 Each living unit has adequate provision for the separate storage of clean linen and dirty linen.

____2.5.1.3.13.1 Dirty linen and laundry are removed from each living unit daily, where necessary, or are otherwise taken care of in a sanitary and appropriate manner.

2.5.2 Staffing and Staff Responsibilities

Definitions

Living-unit staff are those direct-contact staff who are responsible for providing, in the living unit, services to residents that are required by the *Standards*.

In computing living-unit staff-to-resident ratios, staff other than regular living-unit staff may be counted for the proportion of their time that is spent in providing the services required of living-unit staff. If, for example, teachers, food service staff, therapists, or others work with residents during meal times in order to instruct them in self-feeding skills (which is a living-unit staff responsibility), the time so spent may be counted as living-unit staff time. Similarly, living-unit supervisory staff may be counted as direct-contact staff for only the proportion of their time that is spent in providing the direct services to residents that are described in the *Standards*.

Principles

Sufficient, adequately trained, and competent staff must be available to conduct living-unit programs that meet the requirements of the *Standards*. The primary responsibility of living-unit staff must be the care and development of the residents. To fulfill their responsibilities for designing and providing development-enhancing programming, living-unit staff must receive instruction, supervision, and consultation from appropriate professional staff.

The staff-to-resident ratios stated below are the Council's estimates of the minimum number of staff that should be present and on duty on each shift daily in order to conduct a living unit program that is in full compliance with the *Standards*. The ratios do not include allowances for absences for meals, coffee breaks, and so forth. Consequently, the ratios do not mean that the exact number of staff indicated must be present at every moment during the shift. The ratios are minimal, and they are based on the assumption that the major portion (that is, more than half) of the time of living-unit staff will be spent in direct care, development, and training activities with residents, as distinguished from such related activities as administering and charting medications, completing reports and keeping records, housekeeping (including care of clothing and linens), food preparation and serving, escorting residents, staff meetings, and inservice training.

Because the ratios are expressed in terms of the number of residents present in the living unit, fewer staff are necessary when residents are engaged in activities outside the living unit. (If no residents are present, no staff need be present.) The services detailed in the *Standards* must be accomplished, however, in accordance with the needs of the residents served.

Standards pertaining only to agencies providing congregate living services

____2.5.2.1* The primary responsibility of living unit staff is to attend to the care and development of the residents.

____2.5.2.1.1* Living-unit staff train residents in activities of daily living and in the development of self-help and social skills, as specified in Section 1.4.3.

____2.5.2.1.2* Living-unit staff are responsible for the development and maintenance of a warm, family- or home-like environment that is conducive to the achievement of optimal development by the residents.

____2.5.2.1.3* Appropriate provisions are made to assure that the efforts of the staff are not diverted from their responsibilities to the residents by excessive housekeeping and clerical duties or other non-resident-care activities.

____2.5.2.2* Reasonable stability is maintained in the assignment of staff, thereby permitting the development of a consistent interpersonal relationship between each resident and one or two staff members.

____2.5.2.3* A person is specifically assigned responsibility for providing an organized, developmental program of physical care, training, and recreation to the residents in each program group.

____2.5.2.4* The individual program plan for each resident is available to staff in each living unit.

____2.5.2.4.1* Members of the living-unit staff from at least two shifts participate with the interdisciplinary team in planning, implementing, monitoring, and reviewing the resident's individual program plan.

____2.5.2.4.2* There is an effective and ongoing flow of information concerning the resident among all shifts of living-unit staff, so that staff from all shifts can be considered to participate in planning, implementing, monitoring, and reviewing the resident's individual program plan.

____2.5.2.4.3* There are established and effective channels of communication among all programs and services for the purpose of contributing to planning, implementing, and monitoring individual program plans.

____2.5.2.5* An activity schedule for each resident is available to living-unit staff and implemented daily.

____2.5.2.5.1* Activity schedules do not permit "dead time" of more than one hour continuous duration.

____2.5.2.5.2* Activity schedules allow for individual or group free activities, with appropriate materials, as specified by the resident's interdisciplinary team.

____2.5.2.6 A current inventory is kept of each resident's personal effects, including clothing.

____2.5.2.6.1 The person(s) responsible for the agency's resident-clothing program is trained or experienced in the selection, purchase, and maintenance of clothing, and has knowledge of the design of clothing for handicapped individuals relevant to these activities.

____2.5.2.7* Living-unit staff are administratively responsible to a person whose training and experience is appropriate to the residential program.

____2.5.2.8* The title applied to living-unit staff is appropriate to the kind of residents with whom they work and the kind of interaction with residents in which they engage.

____2.5.2.9* The clothing worn by living-unit staff while on duty is appropriate to the program of the unit in which they work, and consistent with attire worn in the community.

2.5.2.10 The daily ratio of on-duty, living-unit staff to residents present in units serving severely and profoundly retarded residents; moderately and severely physically handicapped residents; residents who are aggressive, assaultive, or security risks, or who manifest severely hyperactive or psychotic-like behavior; and other residents who require considerable adult guidance and supervision is not less than:

____2.5.2.10.1 1:4 on the first shift,

____2.5.2.10.2 1:4 on the second shift, and

____2.5.2.10.3 1:8 on the third shift.

2.5.2.11 The daily ratio of on-duty, living-unit staff to residents present in units serving other residents requiring training in basic independent-living skills is not less than:

____2.5.2.11.1 1:8 on the first shift,

____2.5.2.11.2 1:4 on the second shift, and

____2.5.2.11.3 1:16 on the third shift.

2.5.2.12 The daily ratio of on-duty, living-unit staff to residents present in units serving residents in educational, vocational training, and sheltered employment programs who have acquired basic independent-living skills and who are away from the living unit for the major portion of the day is not less than:

____2.5.2.12.1 1:16 on the first shift,

____2.5.2.12.2 1:8 on the second shift, and

____2.5.2.12.3 1:16 on the third shift.

____2.5.2.13 Additional staff coverage is provided as necessary during periods of peak activity in the living unit.

Section 3
Achieving and Protecting Rights

Definition

Achieving and protecting rights refers to the fact that individuals are frequently denied their human and civil rights because of a developmental disability. This occurs not only in the course of their everyday life, but also in the course of receiving needed services. Consequently, special attention and effort are required to assure that these human and civil rights are exercised and protected.

Principles

Developmentally disabled individuals should be considered capable of exercising the same human and civil rights enjoyed by other citizens. These rights should be limited or modified only with due process, and then only to the extent necessitated by the individual's disability.

Developmentally disabled individuals should be taught, insofar as possible, to represent their own rights and interests. However, advocates should be available to those individuals who need or desire assistance in this area. Each agency should fulfill an advocacy function on behalf of developmentally disabled individuals as a group.

Formal protective services, including guardianship, should be available to those individuals and families who need or desire them. Each agency should know the procedures for securing guardianship, and should assist families in obtaining guardianship for those individuals who need it.

3.1 Attention to Individual Rights and Responsibilities

Definition

Attention to individual rights involves assisting developmentally disabled individuals to exercise their human and civil rights. Such assistance is rendered by providing services that:

- promote the family's and society's understanding of the individual's rights,
- monitor programs with respect to the exercise of an individual's rights,
- provide advice and guidance in the exercise of an individual's rights, and
- intervene actively in social and legal processes that affect the exercise of an individual's rights.

Since there are no rights without parallel responsibilities, attention must also be directed to the responsibilities assumed by disabled individuals in exercising their rights.

Principles

Individuals with developmental disabilities have the same rights as other citizens, including, but not necessarily limited to, the right to life; to equal access to educational opportunities; to own and dispose of property; to vote; to liberty and the pursuit of happiness; and to express sexuality, including the right to marry and have children. When an individual's right to liberty must be abridged, the individual has a right to the least restrictive and most appropriate environment or alternative available. Developmentally disabled adults who have not been legally determined to be incompetent have the right to decide whether their families shall be involved in the program planning and implementing activities detailed in these *Standards*.

Although most developmentally disabled individuals can exercise their rights as readily as any other citizens, some may be unable to exercise all of their rights all of the time. These individuals may need guidance and assistance, which may occasionally modify or limit certain rights. Every individual should be considered capable of exercising his or her rights unless legally determined to be incapable of doing so. A right should not be modified or limited without due process, and an individual should not be denied the exercise of a right prior to a hearing. Such a hearing should provide for proper representation and for appeal.

Rights must be modified or limited only to the extent made necessary by the individual's disability. Such modifications or limitations should be specific, rather than general or blanket, and they should be periodically reviewed to assure their continued appropriateness to the individual.

Standards pertaining to all agencies

____3.1.1* The agency has a written statement of policies and procedures concerning the exercise and protection of individual rights.

____3.1.1.1* Implementation of the agency's policies and procedures concerning individual rights assures the civil rights of all individuals.

____3.1.1.2* The agency's policies and procedures concerning individual rights define the means of providing or procuring legal counsel to assist individuals in exercising and protecting their rights.

____3.1.1.3* The agency has written procedures for the appeal of agency decisions by an individual or an individual's family.

3.1.2 The agency safeguards the rights of individuals:

____3.1.2.1* by providing them and their families with a written summary of rights and a description of how to exercise them, and

____3.1.2.2 by providing instruction in how to exercise these rights.

____3.1.3* The agency documents its investigations of alleged violations of developmentally disabled individuals' rights, and the actions taken to intervene in such situations.

____3.1.4* A right of a disabled individual is not limited without due process.

____3.1.4.1* When modification of an individual's rights is under consideration, the rights to be modified are specifically explained to the individual; and the individual, the individual's family, and other interested persons are advised of the process involved in modifying such rights.

____3.1.4.2* The affected individual or others acting on the individual's behalf are given an opportunity, in an orderly proceeding, to be heard and to contest a proposed modification of the individual's rights.

____3.1.4.3* The individual's ability to exercise a right proposed to be modified is evaluated by the individual's interdisciplinary team and is documented in the individual program plan.

____3.1.4.4* The modificiation of a right is specific to the individual's ability to exercise it.

____3.1.4.5* Opportunity is provided for appeal concerning modification of an individual's rights.

____3.1.4.6* When a right has been modified, the continuing need for such modification is reviewed when warranted, but at least annually.

____3.1.4.7* A right that has been denied is restored when circumstances justify its restoration.

____3.1.5* The determination of legal incompetence is separate from the determination of the individual's need for residential services, and admission to a residential program does not automatically imply legal incompetence.

____3.1.5.1* There is documentation that the agency seeks, in accordance with applicable state law, a court order for legal detention or commitment of an individual enrolled in a residential program whose release from such program would, in the judgment of responsible agency personnel, constitute a danger, as defined by applicable state law, to either the individual or other persons.

3.1.6 When an individual attains majority or is otherwise emancipated, it is documented that the review of the individual program plan by the interdisciplinary team (see standard 1.3.8) includes consideration of:

____3.1.6.1* the exercise of the individual's civil and legal rights, and

____3.1.6.2* the individual's need for remaining in a residential program. (See also standard 3.3.2.2.)

____3.1.7* The agency has a human rights committee. The committee:

____3.1.7.1* includes individuals served and/or their representatives, and relevantly qualified professionals who, when the committee is reviewing a research project or behavior management plan, are not involved in the project or plan under review;

____3.1.7.2 includes at least one person who is not an agency employee; and

____3.1.7.3 has a statement of its duties and responsibilities.

____3.1.8* The agency has a written statement of policies and procedures for handling cases of neglect or abuse of individuals by agency staff and volunteers. These policies and procedures:

____3.1.8.1 define neglect and abuse,

____3.1.8.2* prohibit neglect and abuse,

____3.1.8.3 provide a mechanism for discovering instances of neglect or abuse,

____3.1.8.4 provide a mechanism for reviewing all charges of neglect or abuse, and

____3.1.8.5 assure that firm disciplinary and appropriate legal action is taken against those who have engaged in neglect or abuse.

3.1.8.6 Alleged instances of abuse or neglect are reported:

____3.1.8.6.1* to the agency's chief executive officer or his designee immediately, and

____3.1.8.6.2 to at least the chairman of the agency's human rights committee within 24 hours.

3.1.8.7 There is evidence that:

____3.1.8.7.1* all alleged instances of abuse or neglect are thoroughly investigated, using specified investigative procedures;

____3.1.8.7.2* at least the preliminary results of such investigations are reported to the chief executive officer or his designee within 24 hours of the report of the incident;

____3.1.8.7.3* the results of the investigation are recorded, with the employee's knowledge, in the employee's personnel record; and

____3.1.8.7.4* sanctions are invoked when an allegation is sustained.

____3.1.8.8* The agency has a written statement of policies and procedures for initiating intervention in cases of alleged abuse or neglect that occur outside the agency to either children or adults for whom the agency has some responsibility.

____3.1.9* The agency has a written statement of policies and procedures that protects the financial interests of individuals served. The agency:

____3.1.9.1* determines which financial benefits an individual is eligible for;

____3.1.9.2* assures that individuals receive the funds that are due them from public and private support programs for incidentals and for special needs (such as specialized equipment);

____3.1.9.3* provides regular, at least annual, accounting to the individual or to the family, as appropriate; and

____3.1.9.4* provides counseling to the individual, and assures appropriate protection of the funds, when large sums of money accrue.

____3.1.10* The agency has a written policy, consistent with applicable federal and state laws and regulations, that protects individuals from exploitation when they are engaged in training and productive work.

3.1.10.1 Individuals served are not involved in the care (feeding, clothing, bathing, escorting, and so forth), training, or supervision of other individuals served unless they:

____3.1.10.1.1* have been trained in the necessary skills,

____3.1.10.1.2* have the humane judgment required to perform these activities,

____3.1.10.1.3* are adequately supervised, and

____3.1.10.1.4* are reimbursed.

3.1.10.2 Individuals who function at the level of staff in occupational or training activities:

____3.1.10.2.1 have the same privileges as staff, and

____3.1.10.2.2* are paid at the commensurate wage level when employed in other than training situations.

____3.1.11* Individuals are permitted to receive money for work performed and to use money for property administration, in a normalized and normalizing fashion, as for example, in performing cash and check transactions and in buying clothing and other items.

____3.1.12* All information contained in the individual's record, including information contained in an automated data bank, is considered confidential.

____3.1.12.1* The agency is responsible for the safekeeping of each individual's record and for securing it against loss, destruction, or use by unauthorized persons.

____3.1.12.2* The individual's record is removed from the agency's jurisdiction and safekeeping only in accordance with a court order, subpoena, or statute.

____3.1.12.3* The agency has written policies governing access to, duplication of, and dissemination of information in the individual's record.

____3.1.12.4* Written consent of the individual or the family, as appropriate, is required for the release of information concerning the individual to persons not otherwise authorized to receive it.

____3.1.12.5 The individual's record is available to the individual or the family, as appropriate, upon request.

____3.1.13* The individual's record includes appropriate authorizations and consents.

____3.1.14* The agency has evidence that the views and opinions of the individual are elicited and considered in defining the processes and structures that affect him or her, unless the individual is clearly unable to communicate in any way.

____3.1.14.1* When appropriate, the wishes and needs of the individual and of the individual's family concerning religious matters are determined and, insofar as possible, fulfilled.

____3.1.14.1.1* The individual is free to choose whether or not to participate in religious activities.

____3.1.14.1.2* Dietary practices of the individual's faith group are observed at the request of the individual or the individual's family, as appropriate.

____3.1.15* The agency maintains active means of informing families of activities related to the individuals served that may be of interest to them.

____ 3.1.15.1* Communications to the agency from families are handled and answered promptly and appropriately.

____3.1.15.2* Agency personnel are permitted to talk with an individual's family concerning the individual's usual day-to-day activities.

____3.1.15.3* In the event of any unusual occurrence concerning an individual, including serious illness or accident, impending death, or death, the individual's next of kin or the person who functions in that capacity is notified promptly and in a compassionate manner, in accordance with written procedures.

____3.1.16* Agency regulations and practices encourage frequent and informal visits home by individuals enrolled in residential programs.

____3.1.17* The individual's family is permitted to visit all parts of the agency that provide services to the individual.

____3.1.17.1 Families and other visitors are encouraged to visit residences.

____3.1.17.1.1* Close relatives of residents are permitted to visit residences at any reasonable hour, without prior notice.

____3.1.17.2* Steps are taken to avoid infringement on the privacy and rights of residents by visitors to residences.

____3.1.17.2.1 Residences provide privacy for visiting (but not special rooms used solely for visiting).

____3.1.18* In structuring visits to the agency, as opposed to visits to individuals served by the agency, steps are taken both to encourage such visits and to consider the sensibilities and privacy of the individuals being served.

____3.1.18.1* Undignified displays, exhibitions, or exposure of individuals served, whether deliberate or unintentional, are avoided; normal sensibility is exercised in speaking about an individual; and the behavior of staff otherwise reflects sensitivity to the needs of the individuals served for privacy and dignity.

____3.1.19* The agency instructs individuals served in the law and in how to obtain assistance if they are arrested.

____3.1.19.1 A means of identifying themselves to law enforcement officials is provided by the agency to individuals served who have communication problems or who desire such a means of identification.

____3.1.20* Except in an emergency, transfer from one residential facility to another is made only with the prior knowledge, and ordinarily the consent, of the individual and/or the individual's family.

____3.1.21* The coroner or medical examiner is notified of deaths, in accordance with state law.

3.1.21.1 If an individual enrolled in a residential program dies:

____3.1.21.1.1 an autopsy is performed after the permission of the individual's next of kin or legal guardian is obtained;

____3.1.21.1.2 the autopsy is performed by a qualified physician who is free of any conflict of interest or loyalty;

____3.1.21.1.3 it is documented that the family is told, if it so desires, of autopsy findings; and

____3.1.21.1.4 when requested by the family, the agency renders as much assistance as possible in making arrangements for dignified burial or cremation.

3.2 Advocacy

Definition

Advocacy is the act or process of representing the rights and interests of an individual or group, so as to realize the rights to which the individual or group is entitled, obtain needed services, and remove barriers to meeting identified needs. Advocacy may be performed by an individual in his or her own behalf (self-representation), or by an individual on behalf of others (personal advocacy), or by an agency on behalf of the group with which it is concerned (agency advocacy).

Principles

All developmentally disabled individuals should have an opportunity to attain self-representation, not only because it is the most desirable level of advocacy, but also because it is an inherent right. When individuals are so disabled or disadvantaged that they cannot satisfy their major needs or effectively represent their own interests in society, they should have advocates who act for them or with them in important functions, and who vigorously support, represent, and safeguard their interests. In addition, agencies should perform a group advocacy function on behalf of disabled individuals as a class.

3.2.1 Self-Representation

Definition

Self-representation is the act or process of representing one's own rights and interests, so as to realize the rights to which one is entitled, obtain needed services, and remove barriers to meeting identified needs.

Principles

Each developmentally disabled individual should realize his or her potential for self-representation, and agencies should assist individuals to develop and exercise this ability.

Standards pertaining to all agencies

____3.2.1.1* The agency provides or obtains a citizenship training program. As appropriate, the program includes, but is not necessarily limited to:

____3.2.1.1.1 voting rights and responsibilities;

____3.2.1.1.2 consumer rights, responsibilities, and protection;

____3.2.1.1.3 organizational membership and participation;

____3.2.1.1.4 awareness and utilization of other advocacy services; and

____3.2.1.1.5 rights, limits, and responsibilities related to societal and employment activities.

____3.2.1.2 Developmentally disabled individuals are prepared, and provided opportunities, for participation in such community activities as conferences, seminars, public hearings, and meetings.

____3.2.1.3 Developmentally disabled individuals have opportunities to express their feelings to the general public by such means as newsletters, newspapers, speakers' bureaus, brochures, television, and radio.

____3.2.1.4 Developmentally disabled individuals are provided opportunities to join consumer organizations that are involved in issues of concern to them, or to form their own self-advocacy groups.

3.2.2 Personal Advocacy

Definition

Personal advocacy is the act or process in which a person befriends a developmentally disabled individual and represents the individual's rights and interests as though they were the person's own, in order to realize the rights to which the individual is entitled, obtain needed services, and remove barriers to meeting the individual's needs.

Principles

Personal advocates should be available to developmentally disabled individuals and their families to help them accomplish specific goals. Consequently, personal advocacy services should provide responsible, informed persons to befriend and assist developmentally disabled individuals who need assistance in solving problems of daily living, increasing competency and independence, obtaining needed services, and exercising their human and legal rights. Agencies providing advocacy services should have clearly established procedures for designating such advocates and beneficiaries.

Personal advocacy services should be organized and administered so that conflicts of interest are avoided, particularly with respect to other services provided to the individuals served. Advocates may be employed by an agency that also provides direct services, as long as independent advocates are available when needed by the individuals served.

Standards pertaining only to agencies providing personal advocacy services

____3.2.2.1 The administration of personal advocacy services is vested in an organizational structure that minimizes conflicts of interest.

____3.2.2.2 Advocates who are independent of the agency providing direct services are available when needed by the individuals served.

____3.2.2.3 The agency has written policies and procedures concerning personal advocacy services.

3.2.2.4 The agency:

____3.2.2.4.1* identifies individuals who need or want personal advocates;

____3.2.2.4.2* provides the individual and, when appropriate, the individual's family with orientation in advocacy services;

____3.2.2.4.3* recruits and selects advocates, and assesses the ability of each candidate to perform competently as an advocate;

____3.2.2.4.4* matches the individual and the advocate in a beneficial relationship;

____3.2.2.4.5* orients and trains advocates on an ongoing basis;

____3.2.2.4.6* provides practical assistance to personal advocates, including assistance in acquiring the legal and professional services that they or the individuals for whom they advocate may need;

____3.2.2.4.7* prevents advocates from assuming legal roles, such as guardian, adoptive parent, or trustee, for the individuals for whom they advocate;

____3.2.2.4.8* evaluates the performance of each advocate at least quarterly;

____3.2.2.4.9* terminates advocacy service at the request of either the advocate or the individual;

____3.2.2.4.10* evaluates the adequacy and effectiveness of the personal advocacy services program when indicated, but at least semi-annually;

____3.2.2.4.11 solicits feedback to determine any need for expansion or modification of personal advocacy services;

____3.2.2.4.12 publicizes the personal advocacy program to consumers, interested citizens, and cooperating agencies; and

____3.2.2.4.13 provides material for use in orienting and training personal advocates and the individuals for whom they advocate.

____3.2.2.5* With proper authorization, the personal advocate monitors the individual's program plan. The advocate is known:

____3.2.2.5.1* to the person(s) responsible for coordinating the individual's program plan, and

____3.2.2.5.2* to the individual's protective services worker.

____3.2.2.6 In accordance with the needs of the individual, the personal advocate provides supportive social activities. These activities include, but are not necessarily limited to:

____3.2.2.6.1 providing companionship in activities of daily living;

____3.2.2.6.2 providing assistance in solving problems of daily living;

____3.2.2.6.3 supplying missing or needed affective relationships, as parent or sibling substitute, or as friend;

____3.2.2.6.4 working to increase the individual's competency and independence;

____3.2.2.6.5 helping to obtain needed services; and

____3.2.2.6.6 challenging agency practices that appear to discriminate against the individual.

Standards pertaining only to agencies not providing personal advocacy services

____3.2.2.7* The agency collaborates with the personal advocacy services agency.

  ____3.2.2.7.1* The agency identifies individuals who need or desire personal advocacy services.

  ____3.2.2.7.2* The agency communicates with the personal advocate and provides opportunities for the advocate's involvement in matters concerning the individual.

____3.2.2.8* If personal advocacy services are not available, the agency has a written plan outlining how it is working with other agencies to make such services available.

3.2.3 Agency Advocacy

Definition

Agency advocacy is a process of social action that identifies the needs of developmentally disabled individuals and acts to support and safeguard their rights and interests.

Principles

The agency should work within the social and governmental structure of the community to eliminate the causes of social problems that affect developmentally disabled individuals. Through public education and information techniques, the agency should urge civic groups and other concerned citizens to work to eliminate social and legal barriers to services for and acceptance of developmentally disabled individuals. To effect such changes, agencies should have clearly established advocacy goals and objectives, as well as methodology and criteria for formulating issues and determining a course of action.

Standards pertaining to all agencies

____3.2.3.1* The agency, in cooperation with other agencies, develops and implements a written plan for agency advocacy. The plan identifies:

  ____3.2.3.1.1 community-wide problems that confront developmentally disabled individuals and their families;

  ____3.2.3.1.2 methods for addressing problems within the service delivery system;

  ____3.2.3.1.3 strategies for addressing legal, legislative, and administrative problems that compromise the rights, privileges, and entitlements of developmentally disabled citizens;

  ____3.2.3.1.4 the strategies to be implemented to achieve the agency's advocacy goals and objectives; and

  ____3.2.3.1.5 the locus of responsibility for assuring that problems identified will be addressed.

____3.2.3.2 The agency periodically, or as the need arises, makes its findings and recommendations known to the public and to the various governmental bodies involved.

____3.2.3.3* The agency encourages, and demonstrates, the participation of individuals and their families or advocates in developing and implementing the agency's advocacy plan.

3.3 Protective Services

Definition

Protective services constitute a range of sociolegal services that facilitate the exercise of individual rights and provide certain supportive and surrogate mechanisms. Such mechanisms assist developmentally disabled individuals to obtain the maximum independence possible, while protecting them from exploitation, neglect, or abuse.

Principles

Protective services, including guardianship, are a necessary component of a comprehensive service delivery system. The increased interaction between developmentally disabled individuals and the general population has resulted in the need for more systematic monitoring of the individual's welfare, backed by whatever legal sanctions are needed.

Protective services should provide consultation, assistance, and protection to developmentally disabled individuals who are unable to meet their own needs without assistance. Accordingly, protective services should be viewed as a range of assistive and remedial services which, depending upon the nature and extent of individual needs, may range from counseling to full guardianship. The primary responsibility of the protective services agency is to assure the provision of protective mechanisms that are prescriptively responsive to the individual's level of ability and disability. Once this level has been determined, the agency must assist the individual, family, and court to achieve the most appropriate legal relationship, which may range from limited or partial guardianship to plenary or total guardianship of both the individual and the individual's property.

Among the essential prerequisites for a humane and legally sound system of protective services is strict adherence to the principle that developmentally disabled individuals are presumed competent and capable of self management, until the contrary has been clearly demonstrated. Whenever the rights of individuals are modified or limited, strict adherence to the provisions of due process must be maintained. When constraints must be placed upon the legal and constitutional privileges of the individual, there must be clear evidence that they represent the least restrictive feasible alternatives.

Protective services should help developmentally disabled individuals to achieve maximum independence and maximum participation in the privileges and responsibilities of citizenship. To achieve these goals and to reduce the need for the more restrictive forms of protective services, the agency should devote adequate attention to counseling, guidance, follow-along, and personal advocacy services. Similarly, by adequately counseling and training the individual's family and other persons significant in the individual's life, the agency can increase sensitivity to the rights of developmentally disabled individuals, to the need for minimizing legal restrictions upon adults, and to the need for responsible use of estate planning and trust instruments to minimize restrictions on the individual in the event of parental incapacity or death.

The staff of the protective services agency should know all state protective and guardianship procedures, and they should be continually and actively involved in the evolution of laws and forms of protective services that enhance responsiveness to individual needs. Laws that place protective services within an agency that also provides direct services should be particularly discouraged. Such laws should be changed in order to avoid possible conflicts of interest.

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Standards pertaining to all agencies

____3.3.1* Protective services are provided or obtained for any developmentally disabled individual in need.

____3.3.2* The agency assists the individual, the family, and the court in determining the need for protective services.

____3.3.2.1 The agency assists the individual, the family, and the court in determining whether guardianship of either the individual or the individual's property, or both, is needed, and whether guardianship of the individual and the individual's property should be combined or separated.

____3.3.2.2* It is documented that the review of the individual program plan by the interdisciplinary team (see standard 1.3.8) includes determination of the individual's need for guardianship, at least when the individual attains majority or otherwise becomes emancipated.

____3.3.2.3 If state law provides for both limited and plenary guardianship, the agency assists the individual, the family, and the court in determining the appropriate level of guardianship, that is, the most limited form required by the individual's needs.

____3.3.2.4 If state law provides for differing levels of guardianship of property, the agency assists the individual, the family, and the court in determining the appropriate level of guardianship, that is, the most limited form required by the individual's needs.

____3.3.3* The agency assists the individual, the family, and the court in assuring that a qualified person or corporate group is available to the developmentally disabled individual who needs guardianship.

Standards pertaining only to agencies not providing protective services

____3.3.4* The agency collaborates with the protective services agency to assure that individuals served receive protective services if needed.

____3.3.5* If a protective services agency is not available, the agency has a written plan outlining how it is working with other agencies to make such services available.

Standards pertaining only to agencies providing protective services

____3.3.6* The protective services agency is independent of any agency providing direct services.

____3.3.6.1 The administration of protective services is vested in an organizational structure that minimizes conflicts of interest.

____3.3.7 The agency provides or obtains financial management assistance for the individuals served.

____3.3.7.1 The agency secures reports annually from guardians or agencies responsible for control of the financial interests of individuals served.

____3.3.7.2 The agency intervenes when an individual's financial interests are mismanaged.

____3.3.8 The agency identifies the range of alternative living arrangements available within the community.

  ____3.3.8.1 The agency updates the availability of placement resources at least annually.

  ____3.3.8.2 The agency identifies and documents use of the least restrictive alternatives in placement.

____3.3.9 The agency obtains homemaker or other assistive services as an alternative to placement.

____3.3.10 The agency monitors the placement of individuals to assure adequate care.

____3.3.11 The agency documents its activities to use less restrictive alternatives before a guardianship procedure is recommended to the individual or family.

____3.3.12 The agency has provisions for short-term, emergency protective services.

Standards pertaining only to agencies providing guardianship services

____3.3.13* The agency obtains for the court an independent assessment of the individual's need for guardianship, to assure that the individual is the primary beneficiary.

____3.3.14 The agency implements a planned program to recruit, select, train, and evaluate guardians.

  ____3.3.14.1 The agency assists guardians in securing the rights, benefits, and services that individuals need and are entitled to.

  ____3.3.14.2 The agency assists the guardian to understand developmental disabilities and to foster increased independence in the individual.

____3.3.15* The agency assures that no guardian has a financial interest in any direct service being provided to the individual.

  ____3.3.15.1 The agency documents its efforts to assure that the guardian of an individual is not a person or agency that provides direct services to, or obtains direct services for, that individual.

  ____3.3.15.2 If guardians are compensated for their services, the agency documents its efforts to assure that such compensation is based on duties performed, rather than on the income or assets of the individual.

  ____3.3.15.3 The agency makes provision for bonding guardians who manage the property or other financial interests of individuals.

____3.3.16 The agency requires each guardian to submit, at least annually, a written activity report for presentation to, and review by, the court.

  ____3.3.16.1 The agency regularly monitors the activities of guardians with respect to the needs of individuals.

____3.3.17 The agency provides or obtains authorized protective custody services, if requested.

____3.3.18 The agency has provisions for temporary guardianship should the need arise.

____3.3.19 The agency assists the individual, the family, and the attorney in the appropriate utilization of such property management devices as wills and trusts.

____3.3.19.1 The agency assists the individual and the family in understanding and implementing the use of testamentary and stand-by guardians, as necessary.

____3.3.19.2 If state law provides for the appointment of a successor guardian, the agency assists the individual, the family, and the court in obtaining the appointment of a suitable successor guardian.

____3.3.20 The agency assists the individual, the family, and the court in assuring that timely and appropriate procedures are available for the smooth continuation or reestablishment of guardianship when the individual attains majority or needs continuation or reestablishment of guardianship.

Section 4
Individual Program Support

Definition

Individual program support refers to those agency activities and resources that must be provided for, and directed to, the support of individual program planning and implementation.

Principles

All of the activities of each agency serving developmentally disabled individuals must be focused on providing or promoting services that will enhance the development of such individuals. This focus must be reflected in the agency's statements of philosophy and purpose; in its administrative organization, policies, and practices; in the way professional services are made available to the individuals served; and in the provision of personnel, facilities, and equipment to support programming efforts.

The agency must have sufficient competent staff to provide required services, and there must be systematic efforts to increase staff competencies and to keep practices current with expanding knowledge. Volunteers should be utilized in any program in which they may increase, directly or indirectly, opportunities for the development of the individuals served.

Case-finding activities should reach out to find, and to offer services to, those developmentally disabled individuals who need assistance. Procedures and services should facilitate entry into a service delivery system. Follow-along services should be available to those individuals and their families who need and desire a long-term relationship with respect to such resources. To facilitate the development of developmentally disabled individuals, appropriate services must also be available to their families.

In order to demonstrate its accountability to the individuals it serves and to the individuals who support it, the agency must systematically evaluate the effectiveness of its programs. Agencies that provide direct services to developmentally disabled individuals must evaluate the effectiveness of those services in terms of the degree to which objectives set for those individuals are achieved.

4.1 Agency Philosophy, Policies, and Practices

Principles

The agency must have a stated philosophy and stated objectives that govern and guide its activities. These statements and the practices derived from them must reflect implementation of the principle of normalization and its corollaries.

Statements concerning philosophy, objectives, and services offered must be available. The length and elaborateness of the required statements will vary with the size and complexity of the agency's operations.

Standards pertaining to all agencies

____4.1.1* The ultimate aim of the agency is to foster those behaviors that maximize the human qualities of developmentally disabled individuals, increase the complexity of their behavior, and enhance their ability to cope with their environments.

  ____4.1.1.1* The agency accepts and implements the principle of normalization.

  ____4.1.1.2* The agency uses the least restrictive alternatives that are consistent with the developmental needs and objectives of the individuals served.

____4.1.2* The agency has a written statement of its philosophy, objectives, and goals. The statement:

  ____4.1.2.1* clearly defines the agency's role and function within its service delivery system;

  ____4.1.2.2 relates the agency's objectives to those of its service delivery system;

  ____4.1.2.3* relates the agency's objectives to the identified needs of the population served by its service delivery system;

  ____4.1.2.4* defines the population that the agency intends to serve, the services that it intends to provide this population, and the modalities that it intends to use in providing these services;

  ____4.1.2.5* describes the agency's concept of its relationship to the families of individuals served;

  ____4.1.2.6 describes the agency's concept of its responsibility, through research, training, and education, for improving methods, understanding, and support for services for developmentally disabled individuals; and

  ____4.1.2.7* is reviewed at least annually and revised as needed.

  ____4.1.2.8* Copies of the agency's statement of philosophy, objectives, and goals are distributed to agency staff, and are available to individuals served, consumer representatives, and the interested public.

  ____4.1.2.9 Each professional service operated by the agency has a written statement of objectives. Objectives are:

____4.1.2.9.1* consistent with the needs of the individuals served;

____4.1.2.9.2 consistent with the agency's philosophy and goals;

____4.1.2.9.3 consistent with currently accepted standards and principles of the profession;

____4.1.2.9.4 consistent with the interdisciplinary approach;

____4.1.2.9.5 consistent with the agency's resources;

____4.1.2.9.6 prepared by appropriate staff, in consultation with other persons, as appropriate;

____4.1.2.9.7 reviewed at least annually and revised as needed; and

____4.1.2.9.8 communicated to all concerned.

____4.1.3* The agency has a description of services offered that is available to the public. The description includes such information as:

____4.1.3.1 the groups served;

____4.1.3.2 any limitations concerning age, length of residence or other service, or type or degree of handicap;

____4.1.3.3 the plan for grouping individuals into program and living units;

____4.1.3.4 the preadmission and admission services offered;

____4.1.3.5 the diagnosis and evaluation services offered;

____4.1.3.6 the means for implementing, through clearly designated responsibility, individual programs in accordance with need;

____4.1.3.7 the developmental environment provided individuals served; and

____4.1.3.8 the procedures for termination of services and follow-up.

____4.1.4* The name of the agency, the names of its components, the terminology used to refer to the individuals served, and the way these individuals are interpreted to the public are appropriate to the agency's purposes and programs and do not unnecessarily stigmatize the individuals served.

____4.1.4.1* Individuals are not referred to as "patients" except in a hospital-medical context, as "kids" or "children" if they are adults, or as "inmates" or "retardates."

____4.1.5 The agency and its service delivery units are located within the community so as to be conveniently accessible to the population served, and so as to have access to necessary generic services.

____4.1.5.1 The community in which the agency is located can meet the needs of the individuals served for generic and specialized services.

____4.1.5.2 The community in which the agency is located can absorb, and is encouraged to absorb, into its cultural life those individuals capable of participation in that life.

____4.1.5.3 The agency is not isolated from the community by socio-cultural features or by historical image.

____4.1.5.3.1 Protection devices (such as fences and security windows), where necessary, are inconspicuous and preserve as normal an environmental appearance as possible.

____4.1.6* The agency documents its efforts to assure that services provided to the individuals it serves by other agencies are in substantial compliance with the applicable standards for quality of services stated in this document.

____4.1.6.1* All contracts for the provision of services by others stipulate that the standards for quality of services stated in this document will be met.

4.2 Case Finding

Definition

Case finding is the process of systematically reaching into the community to identify individuals in need of services, inform individuals and their families of the availability of services, locate needed services, and assist individuals to enter the service delivery system. Case finding refers to identifying individuals who need services that are, or should be, available within the service delivery system, rather than merely identifying individuals who need the services provided by a particular agency.

Principles

The service delivery system must be designed so that individuals in need of services are actively sought out and given the opportunity to obtain needed services. It is essential that all agencies be alerted to the importance of early detection and of easy access to the service delivery system. The case-finding process should be comprehensive, encompassing those agencies and individuals—such as physicians, hospitals, clinics, health departments, schools, clergy, and law enforcement and social welfare agencies—that may be in contact with disabled individuals and their familes.

Standards pertaining to all agencies

____4.2.1* The agency has written policies and procedures concerning its case-finding program. These policies and procedures include, but are not necessarily limited to:

- ____4.2.1.1 identifying other relevant agencies involved in case finding;
- ____4.2.1.2 coordinating case-finding activities with other agencies and practitioners;
- ____4.2.1.3 identifying individuals in need of services, including those who are unable to represent themselves effectively;
- ____4.2.1.4 locating needed services for individuals; and
- ____4.2.1.5 assisting individuals to enter the service delivery system.

4.2.2 The agency has evidence of activities that:

- ____4.2.2.1* identify individuals in need of services;
- ____4.2.2.2* locate services needed by individuals;
- ____4.2.2.3* assist individuals to enter the service delivery system;
- ____4.2.2.4 alert relevent agencies and others of the importance of early detection, especially with high risk populations, and of their roles as case finders; and
- ____4.2.2.5* coordinate its case-finding activities with the case-finding activities of relevant agencies and practitioners.

4.3 Entry, Admission, and Discharge

Definitions

Entry refers to those activities that lead to an individual's enrollment in the service delivery system. Entry into the service delivery system occurs when an agency representative contacts the individual or the family, or when the individual or the family requests the agency's services. Enrollment occurs when direct services are first provided or obtained for the individual. Admission refers to enrollment in a particular program. Discharge refers to termination of services.

Principles

Entry activities should be sufficiently comprehensive to encompass all developmentally disabled individuals who need services, and to lead all such individuals into the service delivery system, without regard to the actual ability of a given agency to supply directly all the services needed. Agency policies and procedures that affect entry into the service delivery system should be regularly reviewed and evaluated to eliminate duplication of activities, lengthy waiting intervals, restricted availability, and inappropriate entry. Entry into the service delivery system should be centralized, in order to provide those in need of services with a single point of contact. If there is no central entry service, each agency must facilitate entry into the service delivery system. Entry procedures should be flexible enough to accommodate a range of individual needs. Agency procedures should assure collection of comprehensive data concerning individuals served, for use in planning, evaluating, and modifying both the agency's activities and the service delivery system.

Standards pertaining to all agencies

4.3.1 The agency's written policies concerning entry procedures stipulate that individuals are accepted for entry services:

____4.3.1.1* without regard to religion, ethnic origin, sex, degree of disability, or ability to pay; and

____4.3.1.2 without regard to the agency's ability to provide direct services.

____4.3.2* The agency obtains, provides, or coordinates any services needed to facilitate entry into the service delivery system.

____4.3.2.1 The agency's hours of operation enable easy accessibility for total family units.

____4.3.2.2 Staff members who are responsible for the entry interview are readily accessible.

____4.3.2.3 Transportation is arranged, or a home visit made if necessary, for the initial interview.

____4.3.2.4 Available sources of funding are identified for the individual and the individual's family, and assistance is provided in securing funding.

____4.3.3* The agency is the point of referral and follow-up for facilitating the individual's entry into the service delivery system.

____4.3.3.1* The agency obtains from the individual, the individual's family, and other sources, the information needed to determine and make appropriate referrals.

____4.3.3.2 The agency uses recorded referral information to make appropriate referrals to other agencies.

____4.3.4 The agency has a waiting list policy and procedures statement that specifies the interim services to be provided individuals who have not been enrolled.

____4.3.5* Laws, regulations, and procedures concerning admission and readmission to, and release from, programs are summarized and available for distribution.

____4.3.5.1* The agency's written policies and procedures define the conditions of discharge and the procedures for reentry if needed.

____4.3.6* Prior to admission to an alternative living arrangement, the agency provides for preplacement visits by the individual and the individual's family to exchange information with the staff relative to the individual's and the family's needs.

____4.3.6.1 Preplacement visits are made to the surrogate family home by the individual; by the individual's family, except when counterproductive to the individual; and by agency staff.

____4.3.6.2* When an individual is placed in an alternative living arrangement, the agency documents the primary beneficiary of the placement: the individual, the individual's family, or the community.

____4.3.7* Only individuals who have had a comprehensive evaluation, conducted by an appropriately constituted interdisciplinary team, are admitted to alternative living arrangements other than temporary assistance arrangements.

____4.3.8* The number of individuals enrolled in a program does not exceed its rated capacity.

____4.3.9* Admission to a program occurs only when it is documented that such admission has been determined to be the optimal available plan.

____4.3.9.1* Where admission to a program is not the optimal measure, but must nevertheless be recommended or implemented, its inappropriateness is clearly acknowledged, and plans are initiated for the continued and active exploration of alternatives.

____4.3.9.2* All admissions to a program are considered temporary, and admissions are time-limited when appropriate.

____4.3.9.3* The individual and the family are counseled, prior to the individual's admission to a program, on the relative advantages and disadvantages of the program and on its temporary nature.

____4.3.10* Upon admission to a residential program, individuals are placed in their program groups and are isolated only upon medical orders for specific reasons.

____4.3.11* A medical evaluation is made by a licensed physician within one week prior to or following an individual's admission to a residential program.

____4.3.12* Planning for discharge includes provision for appropriate services, which may include protective supervision and other follow-up services.

____4.3.12.1* The agency counsels the individual or family that requests termination of agency services on the advantages and disadvantages of such termination.

____4.3.12.2 Prior to transfer from one setting to another, the individual, accompanied by a staff member of the agency from which transfer is to be made and, when appropriate, by the individual's family, visits the setting to which transfer is to be made.

____4.3.12.3* When an individual is transferred from one program to another, the transfer process assures that the receiving program will meet the individual's needs.

____4.3.12.4 Transfer is in the individual's best interests and not for the convenience of agency staff or administration.

____4.3.13* A discharge summary is prepared upon termination of agency services. The discharge summary:

____4.3.13.1* includes a brief recapitulation of findings, events, and progress during the period of service to the individual;

____4.3.13.2* contains specific recommendations and arrangements for future programming and follow-along services;

____4.3.13.3 includes the agency's evaluation of the appropriateness of the reason for terminating agency services, when termination is contrary to the agency's recommendation; and

____4.3.13.4* is entered in the individual's record within seven calendar days after the agency's termination of service.

____4.3.13.5 With the written consent of the individual or the individual's family, as appropriate, a copy of the discharge summary is sent to the person or agency that will be responsible for future programming for the individual.

4.3.14 In the event of the death of an individual enrolled in a residential program:

____4.3.14.1* a copy of the death certificate is placed in the individual's record; and

____4.3.14.2* when an autopsy is performed, provisional anatomic diagnoses are recorded within 72 hours, where feasible, and the complete protocol is made part of the record within three months.

____4.3.15 The agency maintains a log of entries, referrals, follow-up services, dispositions, and reasons for rejection.

____4.3.15.1 Entry-log data are reviewed annually as a basis for planning, evaluating, and modifying the agency's role.

____4.3.15.2 As part of the community coordinating process, entry-log data are shared with other agencies for use in planning, evaluating, and modifying the service delivery system.

____4.3.16 If a central entry service is not available, the agency has a written plan outlining how it is working with other agencies to develop such a service.

4.4 Follow Along

Definition

Follow along means providing for a continuing relationship with the individual and, when appropriate, with the individual's family to assure that changing needs are recognized and appropriately met. This relationship may be life-long if desired. Follow along includes acting as a point of reference for those who have left a service, but who might seek support or guidance as needs arise, and reinitiating services when necessary.

Principles

Follow along should assure the individual of the right to a life-long service if needed and desired. The service should be designed to assure movement toward long-range goals by a process that monitors placement and that provides appropriate support, counsel, and help.

Standards pertaining to all agencies

____4.4.1* The agency provides or obtains follow-along services as needed and desired by the individual or, as appropriate, by the individual's family.

____4.4.2 The agency educates individuals to seek follow-along services when such services are needed to enhance their independence.

____4.4.3 The agency, in concert with other agencies, identifies each individual's primary follow-along agency, in order to promote efficient services and reduce duplication of efforts.

Standards pertaining only to agencies providing follow-along services

____4.4.4 The follow-along service implements a process that monitors the individual's progress and provides supportive services that assure movement toward long-range goals.

____4.4.5* Each individual has a specific point of contact within the agency.

____4.4.6 The individual and the family are informed of the procedures for terminating or reentering a follow-along service program.

____4.4.7 The follow-along service assists with the transition to a new service, as necessary.

____4.4.8* The follow-along service has written procedures to assure that the individual's right to privacy is not violated.

____4.4.9 The follow-along service records the individual's status in the individual's record at least annually.

____4.4.10 The follow-along service has access to information in the individual's records.

4.5 Family-Related Services

Definition

Family-related services encompass those that serve both developmentally disabled individuals and their families. In addition to the home training services and family education services covered in this section, family-related services also include homemaker and sitter/companion services, and temporary-assistance living arrangements covered in Sections 2.2 and 2.3 respectively.

Principles

To meet the developmental needs of developmentally disabled individuals, services must be available to both disabled individuals and their families. Family members should be helped to understand the impact of disability, to improve their relationships with the developmentally disabled individual, and to mobilize their own strengths in coping with the disability in a constructive manner. Family members should receive instruction in ways of facilitating the development of the developmentally disabled individual, including training in specific management techniques. Home training programs should provide continuity and consistency with training programs conducted outside the home. Home training programs should not, however, substitute for training programs conducted outside the home.

4.5.1 Home Training Services

Definition

Home training services are specialized training programs for the individual and/or the family that are primarily conducted within the home.

Standards pertaining only to agencies providing home training services

4.5.1.1 The agency's home training service:

____4.5.1.1.1* develops, with the family, a developmentally sequenced management and training program that is a component of the individual program plan, and that is carried out in the home;

____4.5.1.1.2* instructs the family in how to carry out the program;

____4.5.1.1.3 provides for family use of specialized instructional material;

____4.5.1.1.4 provides information on developmental disabilities and developmental patterns;

____4.5.1.1.5 develops, with the family, a method of assessing the abilities, disabilities, and level of performance of the individual;

____4.5.1.1.6 assists the individual and the family in incorporating the therapy offered by various disciplines into the individual's daily regime;

____4.5.1.1.7 coordinates the individual's activities with services delivered by others;

____4.5.1.1.8 demonstrates special procedures;

____4.5.1.1.9 helps adapt home equipment;

____4.5.1.1.10 helps the family make, or identify resources for obtaining, specialized equipment;

____4.5.1.1.11 assists the family with special clothing adaptations; and

____4.5.1.1.12 provides continuing support and assistance.

Standards pertaining only to agencies not providing home training services

____4.5.1.2* If home training services are not available elsewhere, the agency has a written plan outlining how it is working with other agencies to make such services available.

4.5.2 Family Education Services

Definition

Family education provides opportunities for the individual's family to increase its knowledge of developmental disabilities and its understanding of other concerns relating to the family unit.

Standards pertaining to all agencies

____4.5.2.1* The agency provides or obtains family education opportunities on a regularly scheduled basis and as family needs arise.

____4.5.2.1.1 Family members are involved in the development and evaluation of family education programs.

____4.5.2.1.2 Family education techniques are adapted to the cultural, educational, and economic characteristics of the families being served.

____4.5.2.2* Family members have an opportunity to observe the individual being served in a service setting, without violating the individual's right to privacy.

____4.5.2.2.1 Family observations of the individual being served are discussed with appropriate agency staff.

4.5.2.3 Planned conferences between staff members and individual families are held:

____4.5.2.3.1* on a regularly scheduled basis;

____4.5.2.3.2* as needs arise; and

____4.5.2.3.3* either in or out of the home, as appropriate.

____4.5.2.4 The agency provides or obtains counseling for the individual and, at the individual's request and when appropriate, for the individual's family concerning interpersonal conflicts or conflicts arising from isolated or disorganized families.

____4.5.2.5 The agency provides or obtains parent-to-parent counseling activities for newly identified parents and in times of crisis.

____4.5.2.6 Group meetings are conducted or made available for siblings of developmentally disabled individuals.

____4.5.2.7* A resource library relating to developmental disabilities is available to the family. Library materials include:

____4.5.2.7.1 basic information on developmental disabilities;

____4.5.2.7.2 information on developmental patterns;

____4.5.2.7.3 information on techniques of management and training;

____4.5.2.7.4 information relating to attitudes and feelings toward, and understanding of, developmentally disabled individuals; and

____4.5.2.7.5 instructional materials, including games and toys, and information on their use.

____4.5.2.8 The agency has a program for mobilizing and utilizing parent leadership skills.

____4.5.2.8.1 The agency identifies indigenous leadership within cultural subgroups.

4.6 Professional Services

Definition

Professional services include, but are not necessarily limited to, those provided by individuals trained and qualified in the following disciplines or areas of service: audiology; dentistry, dental hygiene, and dental assisting; education; food, nutrition, and dietetics; legal services; library services; medicine (including both allopathic and osteopathic medicine); music, art, dance, and other activity therapies; nursing; occupational therapy; optometry; pharmacy; physical therapy; podiatry; psychology; recreation (including therapeutic recreation); religion and religious education; social work; speech and language pathology; and vocational rehabilitation.

Principles

All individuals must receive the professional services required to identify and meet their needs. Only the professional services needed by individuals must be made available to them. Such services may be provided by programs operated, or personnel employed, by the agency, or by effective arrangements between the agency and other service providers, including both agencies and individual practitioners. Since many identical or similar services or functions may be rendered competently by persons representing different professions or disciplines, services needed by the individuals served should be provided in an efficient and competent manner, without regard to the professional identification of the persons providing them, unless only members of a single profession are qualified or legally authorized to perform a service. The quality of professional services operated by the agency should at least equal the quality of such services generally provided to all persons.

In addition to providing services through direct contact with developmentally disabled individuals, professional personnel should expand the services they deliver by providing stimulation, leadership, training, and other assistance to other persons working with the individuals served, so that relevant professional knowledge can be implemented throughout the individual's programs and daily activities. All professional services must be rendered in an interdisciplinary fashion.

Standards pertaining to the delivery of professional services appear throughout this document, and the fact that a profession or discipline is not mentioned in this section is not to be construed to mean that there are no standards pertaining to it. Only standards that could not be located more conveniently elsewhere are included in this section.

Standards pertaining to all agencies

____4.6.1* All individuals, regardless of age or degree of disability, receive the professional services that they need.

4.6.1.1 Professional services include, as appropriate to the individual served, both:

____4.6.1.1.1* diagnosis and evaluation, including the identification of developmental level and needs; and

____4.6.1.1.2* treatment services.

____4.6.1.2* Professional personnel participate, as appropriate, on interdisciplinary teams.

____4.6.1.3* Professional services include preventive services designed to prevent deterioration or further loss of function by all individuals, but especially by those individuals with multiple and severe handicaps.

____4.6.1.4* In addition to providing services through direct contact with individuals, professional personnel expand the services they deliver by providing stimulation, leadership, training, and other assistance to other persons working with individuals, so that relevant professional knowledge can be implemented throughout the individuals' programs and daily activities.

____4.6.2* The quality of professional services operated by the agency at least equals the quality of such services generally provided to all persons, as judged by such criteria as physical facilities, qualifications of personnel, duration and intensity of service, and equipment and supplies.

____4.6.2.1* Each member of the agency's professional staff is familiar with and adheres to professional ethics and standards of practice, such as those set forth in the codes of ethics and standards or practice promulgated by relevant professional organizations.

____4.6.2.1.1 It is recognized that professional ethical codes apply to work with developmentally disabled individuals.

____4.6.2.2* Each professional service operated by the agency maintains the records needed for providing adequate services to individuals served.

____4.6.2.2.1* When another agency assumes responsibility for services to an individual, a summary of the appropriate record is forwarded to that agency, with the permission of the individual or, if appropriate, of the individual's family.

4.6.2.3 Professional staff members offer consultation and instruction, as appropriate, to:

____4.6.2.3.1 the individual's family; and

____4.6.2.3.2 other agencies, organizations, and persons in the community.

____4.6.2.4 Professional staff members participate, as appropriate, on agency committees concerned with the agency's programs and operations, including administrative and policy-making committees.

____4.6.3* The agency maintains effective arrangements with other agencies or with practitioners, including consultants, through which services not regularly provided within the agency can be obtained promptly when needed.

4.6.4 Audiological services: see especially Section 1.

4.6.5 Dental services: see especially Section 1.

4.6.6 Educational services: see especially Section 1.

____4.6.7* Food services provided by the agency provide a nourishing, well-balanced diet, consistent with local customs, to all individuals served. (See also Section 1.)

4.6.7.1 The agency's food and nutrition services are responsible for:

____4.6.7.1.1* menu planning;

____4.6.7.1.2* initiating food orders or requisitions;

____4.6.7.1.3* establishing specifications for food purchases, and assuring that such specifications are met;

____4.6.7.1.4* storing and handling food;

____4.6.7.1.5* food preparation;

____4.6.7.1.6* food serving; and

____4.6.7.1.7* ongoing instruction and supervision of food handlers in personal hygiene and sanitary food handling practices.

____4.6.7.2* Menus are planned to meet individuals' food and nutrition needs, in accordance with the *Recommended Dietary Allowances* of the Food and Nutrition Board of the National Research Council, adjusted for age, sex, activity, and disability.

____4.6.7.2.1* Menus are written in advance.

____4.6.7.2.2* The daily menu is posted in food preparation areas.

____4.6.7.2.3* Menus provide a sufficient variety and amount of food at each meal. Menus are:

____4.6.7.2.3.1* different for the same days of each week, and

____4.6.7.2.3.2* adjusted for seasonal changes.

____4.6.7.2.4 When changes in the menu are necessary, substitutions provide equal nutritive values and are noted.

____4.6.7.2.5* Records of menus served are kept on file for at least 30 days.

4.6.7.3 Foods are prepared by methods that:

____4.6.7.3.1* conserve nutritive value,

____4.6.7.3.2* enhance flavor, and

____4.6.7.3.3* enhance appearance.

____4.6.7.3.4 A file of tested recipes adjusted to appropriate yield is maintained.

4.6.7.4 Food is served:

____4.6.7.4.1 as soon as possible after preparation, in order to conserve nutritive value;

____4.6.7.4.2 in an attractive manner;

____4.6.7.4.3* in appropriate quantity;

____4.6.7.4.4* at appropriate temperature; and

____4.6.7.4.5* with appropriate utensils.

____4.6.7.5* Records of food purchased for preparation are filed and maintained for at least 30 days.

____4.6.7.5.1 At least a one-week supply of staple foods and a two-day supply of perishable foods are maintained on the premises.

4.6.8 Legal services: see especially Section 3.

4.6.9 Library services that are operated by the agency provide (see also especially Section 1):

____4.6.9.1 informational, recreational, and educational materials (including media to stimulate sensory development) and services that are appropriate to individuals at all stages of communicative development; and

____4.6.9.2 to the agency's staff: informational, educational, and research materials relevant to developmental disabilities.

4.6.10 Medical services: see especially Section 1.

4.6.11 Music, art, dance, and other activity therapies: see especially Section 1.

4.6.12 Nursing services: see especially Section 1.

4.6.13 Occupational therapy services: see especially Section 1.

4.6.14 Optometric services: see especially Section 1.

4.6.15 If pharmacy services are provided by the agency, a pharmacist (see also especially Sections 1 and 5):

____4.6.15.1* takes a medication history upon the individual's admission;

____4.6.15.2* receives the original, or a direct copy, of the physician's drug treatment order;

____4.6.15.3* maintains a drug profile for each individual, including a record of all medications dispensed, with quantities and frequency of refills;

____4.6.15.4* reviews and records the drug regimen, and any changes, for potential adverse reactions, allergies, interactions, contraindications, rationality, and laboratory test modifications; and advises the physician of any recommended changes, with reasons and with an alternative drug regimen;

____4.6.15.5* regularly reviews the record of each individual on medication, and has contact with selected individuals with potential problems, noting in their records and reporting to physicians any observations of response to drug therapy, and of adverse reactions and over- or under-utilization of drugs;

____4.6.15.6 provides instruction and counseling on the correct use of drugs, as prescribed by the attending practitioner, to individuals and/or their families;

____4.6.15.7 participates in drug abuse education programs;

____4.6.15.8* establishes quality specifications for drug purchases, and assures that they are met;

____4.6.15.9 is responsible for all drug storage;

____4.6.15.10 provides the agency's staff with pharmacological and other necessary information on investigational drugs, including dosage form, dosage range, storage, adverse reactions, usage, and contraindications;

____4.6.15.11 is responsible for providing and maintaining emergency kits; and

____4.6.15.12* is responsible for the compounding, packaging, labeling, and dispensing of drugs, including samples and investigational drugs.

____4.6.15.13* Wherever possible, drugs that require dosage measurements are dispensed by the pharmacist in a form ready to be administered to the individual.

____4.6.15.14* The agency's pharmacy contains a formulary system that is approved by the responsible physician and pharmacist, and by other appropriate staff.

____4.6.15.14.1* Copies of the agency's formulary and of the current *American Hospital Formulary Service* are appropriately located and available.

____4.6.15.14.2* The agency's pharmacy contains current pharmaceutical reference material that provides adequate information concerning drugs.

4.6.16 Physical therapy services: see especially Section 1.

4.6.17 Podiatric services: see especially Section 1.

4.6.18 Psychological services: see especially Section 1.

4.6.19 Recreation services: see especially Section 1.

4.6.20 Religious services that are provided by the agency (see also especially Sections 1 and 3):

____4.6.20.1 afford opportunities for developmentally disabled individuals to participate in religious activities of their choice, and

____4.6.20.2 make efforts to integrate them into religious congregations of their preference.

4.6.21 Social work services: see especially Section 1.

4.6.22 Speech and language pathology services: see especially Section 1.

4.6.23 Vocational rehabilitation services: see especially Section 1.

4.7 Staffing and Staff Qualifications

Principles

There must be sufficient, adequately trained, and appropriately qualified staff to provide services that meet the requirements of the standards. Services must be provided by competent persons who are licensed or certified, when such licensure or certification is legally required for offering services to the general public; and services must be performed by persons who are legally authorized to perform them, when such performance is regulated by law. Nonlicensed or noncertified personnel working in areas for which licensure or certification is legally required should work under the direct supervision of licensed or certified persons. A fully qualified person should be responsible for maintaining standards of professional and ethical practice in each professional service operated by the agency.

It is not possible to stipulate professional staff ratios that are generally applicable to agencies for at least three reasons:

1) the needs of individuals served vary from one agency to another;
2) the needs of individuals may be met through a variety of program approaches; each agency has some options concerning the kinds of programs that it will use to meet the needs of the individuals served; and
3) the roles and functions of professionals vary among agencies; many identical or similar services or functions may be performed competently by individuals of different professions, depending upon the knowledge and skills possessed by the particular persons involved.

For these reasons, each agency must determine the numbers of professional staff that are necessary to provide active and adequate services. This determination must be based upon an appraisal of the needs of the individuals served, the programs utilized to meet those needs, and the roles and functions of the particular professionals who are employed.

Professional qualifications are detailed in this section only when they are in addition to those required of all professional personnel by virtue of (a) the requirement that professionals be licensed, certified, or registered as required by the state in which the agency is located or, in the absence of such state requirements, that they be eligible for recognition by the appropriate state or national professional organization, when such recognition is available, or have documented equivalent training and/or experience and (b) the requirement that all personnel providing services at above the professional entry level have had training and experience in working with developmentally disabled individuals.

Standards pertaining to all agencies

4.7.1 To conduct its programs in accordance with the standards specified in this document, the agency has:

____4.7.1.1* sufficient staff, and

____4.7.1.2* appropriately qualified staff.

____4.7.2* Agency personnel are licensed, certified, or registered as legally required for offering services to the general public in the state in which the agency is located.

____4.7.2.1 Agency personnel for whom state licensure, certification, or registration is not required are eligible for certification or recognition by the appropriate state or national professional organizations, when such certification or recognition is available, or have documented equivalent training and/or experience.

____4.7.2.2* Agency personnel for whom state licensure, certification, or registration is not required, but who work in areas for which such licensure, certification, or registration is required, work under the direct supervision of licensed, certified, or registered personnel.

____4.7.3 Each person providing professional services at above professional entry level has had training and experience in working with developmentally disabled individuals.

____4.7.4 Persons providing services are able to communicate with the individuals served and are familiar with their ethnic and cultural backgrounds.

____4.7.5* For each professional service operated by the agency, a person fully qualified to render the service in the state in which the agency is located is designated to be responsible for maintaining standards of professional and ethical practice.

____4.7.6* Depending upon the size and scope of the agency's food and nutrition services, such services are directed by one of the following:

a. a dietitian who is eligible for membership in the American Dietetic Association, and preferably eligible for registration by the Association, or who has documented equivalent training and/or experience; or a nutritionist who has a master's degree in foods, nutrition, or public health nutrition, who is eligible for membership in the American Dietetic Association, and preferably eligible for registration by the Association, or who has documented equivalent training and/or experience; and who, unless employed by an agency that also employs a dietitian, has had experience in institutional food management;

b. a food service manager who has a bachelor's degree in foods, nutrition, or a related field, and who receives consultation from a dietary consultant; or

c. a responsible person who has had training and experience in meal management and service, and who receives consultation from a dietary consultant.

____4.7.6.1* When food services are not directed by a nutritionist or dietitian, regular consultation with a nutritionist or dietitian is documented.

____4.7.6.1.1 An evaluation procedure is established to determine the extent of implementation of the consultant's recommendations.

____4.7.6.2* Modified diets are planned, prepared, and served by persons who have received adequate instruction.

____4.7.7 The person responsible for maintaining standards of professional and ethical practice in the delivery of the agency's library services has a fifth-year degree in library services from a program accredited by the American Library Association, or has documented equivalent training and/or experience, or has access to a consultant so qualified.

4.7.8 The nurse responsible for maintaining standards of professional and ethical practice in the delivery of the agency's nursing services:

____4.7.8.1 has had three years of professional experience, two years of which have been in working with developmentally disabled individuals;

____4.7.8.2 has demonstrated competence in administration and supervision, as appropriate to the agency's program; and

____4.7.8.3 has at least a bachelor's degree in nursing, and preferably a master's degree in nursing or in an area related to the program.

4.7.8.3.1 A nurse practicing as a nurse practitioner:

____4.7.8.3.1.1* has completed a formal training program approved by the American Nurses' Association or certified by a university school of nursing, or has documented equivalent training and/or experience; and

____4.7.8.3.1.2* has a designated medical preceptor who is available as needed.

____4.7.9 Music therapists are graduates of a curriculum accredited by, or in collaboration with, the National Association for Music Therapy, or have documented equivalent training and/or experience.

4.7.10 The occupational therapist responsible for maintaining standards of professional and ethical practice in the delivery of the agency's occupational therapy services:

____4.7.10.1 has had three years of professional experience, two years of which have been in working with developmentally disabled individuals;

____4.7.10.2 has demonstrated competence in administration and supervision, as appropriate to the agency's program; and

____4.7.10.3 preferably has a master's degree in an area related to the program.

____4.7.10.4* Occupational therapists are graduates of a curriculum accredited by, or in collaboration with, the American Occupational Therapy Association, or have documented equivalent training and/or experience.

4.7.11 The physical therapist responsible for maintaining standards of professional and ethical practice in the delivery of the agency's physical therapy services:

____4.7.11.1 has had three years of professional experience, two years of which have been working with developmentally disabled individuals;

____4.7.11.2 has demonstrated competence in administration and supervision, as appropriate to the agency's program; and

____4.7.11.3 preferably has a master's degree in an area related to the program.

____4.7.11.4* Physical therapists are graduates of a curriculum accredited by, or in collaboration with, the American Physical Therapy Association, or have documented equivalent training and/or experience.

____4.7.12 The services of at least one doctoral-level psychologist are available to the agency.

____4.7.12.1 The person responsible for maintaining standards of professional and ethical practice in the delivery of the agency's psychological services is a doctoral-level psychologist.

____4.7.12.2 All psychologists providing services in the agency possess the qualifications required for membership in the American Psychological Association, or have documented equivalent training and/or experience.

____4.7.13 The person responsible for maintaining standards of professional and ethical practice in the delivery of the agency's recreation or therapeutic recreation services has:

a. a master's degree in therapeutic recreation and one year of experience in a recreation program serving disabled individuals; or

b. a master's degree in recreation and two years of experience in a recreation program serving disabled individuals; or

c. a bachelor's degree in therapeutic recreation and three years of experience in a recreation program serving disabled individuals; or

d. a bachelor's degree in recreation and four years of experience in a recreation program serving disabled individuals; or

e. the qualifications required for professional registration by the National Therapeutic Recreation Society; or

f. documented equivalent training and/or experience.

____4.7.14 Religious services provided by the agency are under the direction of a person who, in keeping with the size and nature of the agency, is one of the following:

a. a member of the clergy who is certified for work with developmentally disabled individuals by a recognized certifying agency, or has documented equivalent training and/or experience; or

b. a religious educator with at least a bachelor's degree and theological training, a period of supervised clinical experience in working with developmentally disabled individuals, and endorsement by his or her religious community; or

c. an ordained clergyperson in good standing with his or her religious community, functioning within the geographic area in which the agency is located, who has a basic understanding of the needs of developmentally disabled individuals.

____4.7.15 The agency has available to it a social worker who:

a. has a master's or doctoral degree from an accredited school of social work and two years of post-master's experience in the field of social welfare, or

b. has the qualifications required for certification by the Academy of Certified Social Workers, or

c. has documented equivalent training and/or experience.

4.7.15.1 Social workers providing service to the agency:

____4.7.15.1.1 possess the qualifications required for full membership in the National Association of Social Workers, or have documented equivalent qualifications; and

____4.7.15.1.2 work under the supervision of a social worker who is qualified as stated in standard 4.7.15.

____4.7.16 Vocational rehabilitation counselors have:

a. a master's degree in rehabilitation counseling; or

b. a master's degree in a related area, plus training and skill in the vocational rehabilitation process; or

c. a bachelor's degree and work under the direct supervision of a person with the qualifications stated above.

____4.7.16.1 Vocational rehabilitation personnel providing training to individuals are either vocational instructors certified by the appropriate state agency, or tradesmen who have attained at least journeyman status.

4.7.17 The person responsible for conducting the agency's volunteer services program has:

____4.7.17.1 a bachelor's degree, or education or experience in the administration of volunteer services;

____4.7.17.2 two years of experience in volunteer services or a related area; and

____4.7.17.3 knowledge of community organization.

4.7.18 Persons employed or otherwise participating in the agency's transportation system meet the following criteria:

____4.7.18.1* all drivers have current, valid, and appropriate licenses;

____4.7.18.2* drivers and aides are trained in managing individuals with developmental disabilities; and

____4.7.18.3* drivers and aides are trained in first aid and medical emergencies.

____4.7.19 Supportive personnel employed in professional services operated by the agency include, as appropriate, receptionists, clerical personnel, technicians, escort and other aides, and janitorial and housekeeping personnel.

4.8 Staff Training

Definition

Staff training is an organized program to prepare new employees to perform their assigned duties competently, and to maintain and improve the competencies of all employees.

Principle

Because meeting the needs of developmentally disabled individuals requires the efforts of competent personnel who maintain currency with expanding knowledge in their fields, each agency must arrange for a staff training program.

Standards pertaining to all agencies

____4.8.1* The agency provides a staff training program. The staff training program includes:

____4.8.1.1* orientation for all new employees to acquaint them with the philosophy, organization, programs, practices, and goals of the agency;

____4.8.1.2* induction training for each new employee;

____4.8.1.3* inservice training for employees who have not achieved the desired level of competence, and opportunities for continuous inservice training to update and improve the skills and competencies of all employees;

____4.8.1.4* supervisory and management training for all employees in, or candidates for, supervisory positions;

____4.8.1.5 training programs designed to facilitate an increase in personal effectiveness, as well as lateral and upward movement;

____4.8.1.6* training in the interdisciplinary approach;

____4.8.1.7* training in implementing the principle of normalization;

____4.8.1.8 training in properly and competently assuming responsibility for talking with an individual's family concerning the individual's usual day-to-day activities;

____4.8.1.9* training in administering first aid, including the Heimlich maneuver, in the presence of accident or illness;

____4.8.1.10 current information concerning prevention;

____4.8.1.11 provision for educating staff members as research consumers;

____4.8.1.12 studies to assess the training needs of staff; and

____4.8.1.13 participation of appropriate staff.

4.8.2 Direct-contact personnel are trained in:

____4.8.2.1* detecting signs of illness or dysfunction that warrant medical or nursing intervention,

____4.8.2.2* basic skills required to meet the health needs and problems of the individuals served, and

____4.8.2.3* use of proper feeding techniques.

____4.8.2.4* Personnel are not assigned to work with individuals with seizure disorders and physical handicaps until they have received instruction in proper management of such individuals.

____4.8.2.5 Personnel working with individuals who present risk of injury to others receive specific training in physical intervention techniques, the aim of which is to prevent injury to either employees or individuals.

____4.8.3* Completed training is documented in each employee's personnel record.

4.8.4 The agency makes provisions for all staff members to improve their competencies through such means as:

____4.8.4.1 attending staff meetings;

____4.8.4.2 attending seminars, conferences, workshops, and institutes;

____4.8.4.3 attending college and university courses;

____4.8.4.4 visiting other agencies;

____4.8.4.5 participating in professional organizations;

____4.8.4.6 conducting research;

____4.8.4.7 publishing studies; and

____4.8.4.8 having access to a professional library.

____4.8.5 The services of consultants not directly associated with the agency are available to the staff of each of its programs.

____4.8.6* A staff member is designated to be responsible for staff training. This person has:

____4.8.6.1 an appropriate combination of academic training and relevant experience, and

____4.8.6.2 demonstrated competence in organizing and directing staff training programs.

____4.8.7 Adequate, modern educational media equipment (such as overhead, filmstrip, motion picture, and slide projectors; screens; models and charts; and video tape systems) is available to conduct the inservice training program.

4.9 Volunteer Services

Definition

The volunteer services program is an organized and supervised activity in which the varied skills of unpaid personnel are utilized to support and supplement the efforts of paid agency staff.

Principles

Agency activities should be enhanced and expanded through the use of volunteers, and a volunteer program should be part of each agency's operation. The agency must be willing to devote considerable time and energy to this program. No matter how small the agency, the volunteer program will require at least part-time attention by a staff member. Although personnel practices relating to volunteers need not be as formalized as those established for staff, such practices should be clear. In addition to providing direct and indirect services to developmentally disabled individuals, an effective volunteer program will facilitate positive relationships between the agency and the community that it serves.

Standards pertaining to all agencies

____4.9.1* The agency either uses volunteers to support and supplement the activities of its paid staff, or documents its efforts to do so.

  ____4.9.1.1* Volunteers provide direct or indirect services that are based on the needs of individuals served, on staff requests, and on volunteer skills; and that enhance programs, develop social competence, and build self-esteem.

____4.9.2* Volunteer services are available to individuals in accordance with their needs, regardless of age, ability, or handicaps.

____4.9.3* The agency follows established written policies concerning recruitment, selection, training, assignment, supervision, evaluation, recognition, and separation of volunteers.

  ____4.9.3.1* Volunteer participation is open to persons of both sexes; to persons of all races, creeds, and national origins; and to persons of appropriate ages.

  ____4.9.3.2* Volunteer participation complies with state laws, such as those relating to labor and insurance.

  ____4.9.3.3* Staff members responsible for agency programs utilizing volunteers are responsible for providing such volunteers with on-the-job training, supervision, and consultation.

  ____4.9.3.4 A volunteer services advisory committee, composed of representatives from the agency, the individuals served, and the community, plans, reviews, and recommends improvements in the volunteer program.

____4.9.4* An agency staff member is designated to be responsible for conducting the volunteer services program. The staff member:

____4.9.4.1* devotes sufficient time to the administration of the program, and

____4.9.4.2 has the same relationship to volunteers as a personnel officer has to paid employees.

4.9.5 Volunteer services staff provide the following services:

____4.9.5.1 orientation of staff and volunteers in the need for, and philosophy of, volunteer services;

____4.9.5.2 identification of how and where volunteers can be utilized;

____4.9.5.3 assistance in developing training for volunteers; and

____4.9.5.4 development, in collaboration with appropriate staff, of job descriptions for volunteers.

____4.9.6 The agency maintains accurate records concerning volunteer services. Such records include, but are not necessarily limited to:

____4.9.6.1 the types, hours, and results of volunteer services provided;

____4.9.6.2 individuals and organizations providing volunteer services;

____4.9.6.3 materials and monies received; and

____4.9.6.4 operational expenditures.

4.10 Governance and Management

Definitions

The governance of an agency determines its mission and purpose. Its management or administration is responsible for planning, organizing, directing, controlling, and coordinating the activities of the organization, so that its mission and purpose are fulfilled.

Principles

No single organizational or administrative model is appropriate for all agencies serving developmentally disabled persons. The model chosen for an agency must be appropriate for meeting the needs of the individuals served. Management and administrative activities must be means to an end, rather than ends in themselves.

The governance and administration of the agency must provide for appropriate participation of consumers, consumer representatives, and representatives of the public in developing agency objectives and policies; and must be accountable to those who are served by the agency and those who support it.

Management of the agency should provide for communication among, and participation of, all levels of staff through such means as membership on committees concerned with agency affairs. The number and size of such committees will vary with the size and complexity of the agency. In a small agency, a single committee or a committee-of-the-whole may suffice.

4.10.1 Governing Body and Administration

Definition

The agency's governing body, whether an individual or a group, is the policy-making authority. It exercises general direction over the affairs of the agency, and establishes policies concerning the operation of the agency and the welfare of the individuals served. The governing body provides for administration of the agency by appointing a chief executive officer to implement its policies.

Standards pertaining to all agencies

4.10.1.1 Services operated by the agency are organized to:

____4.10.1.1.1* focus on meeting the needs of the individuals served; and

____4.10.1.1.2* assure the individuals served freedom of movement from one level of achievement to another within the agency, and from the agency to other services.

____4.10.1.2* The agency has documentary evidence of its source of operating authority:

a. A public agency has documents that describe the administrative framework of the governmental department in which it operates.

b. A private agency has its charter, its constitution and bylaws, and, where required, its state license.

____4.10.1.3* The governing body of the agency exercises general direction over the agency and establishes policies concerning the operation of the agency and the welfare of the individuals served. If the governing body is a board:

____4.10.1.3.1 its members visit all program components of the agency during operating hours, and

____4.10.1.3.2 the agency provides orientation and training for new members.

____4.10.1.4* The agency's governing body establishes a job description for the position of chief executive officer, including appropriate qualifications of education, experience, personal factors, and skills.

____4.10.1.4.1* The agency's chief executive officer has administrative ability, leadership ability, and an understanding of developmental disabilities.

____4.10.1.4.2* The agency's chief executive officer has had training and experience in the administration of human services.

____4.10.1.4.3 The agency's chief executive officer participates in continuing, organized management training activities appropriate to his or her responsibilities.

____4.10.1.4.4 Where the agency's chief executive officer is required to have had training in a specific professional discipline, the discipline is relevant to the agency's programs.

____4.10.1.5* The agency's governing body employs a chief executive officer qualified as specified above, and delegates to him or her authority and responsibility for the management of the affairs of the agency in accordance with written policy.

____4.10.1.6* The agency's chief executive officer designates a person to act for him or her in his or her absence.

____4.10.1.6.1 When an assistant chief executive officer is employed, the qualifications required for this position conform to those stated herein for the agency's chief executive officer.

____4.10.1.6.2 During operating hours, a person designated by the agency's chief executive officer, or by the person acting for him or her, has authority for the supervision of the agency.

____4.10.1.6.3* All employees on duty know who is responsible for supervision of the agency at any given time, and know exactly whom to contact and what procedures to institute in the event of any emergency.

____4.10.1.7 The governing body and management of the agency provide for meaningful and extensive consumer and public participation in the development of agency objectives and policies through the following means:

a. If the agency has a governing board, its members include interested citizens and relevantly qualified professionals presumed to be free of conflicts of interest, and, if the agency provides direct services, individuals served by the agency and/or their representatives.

b. If the agency does not have a governing board, its governing body actively seeks advice from an advisory board that includes interested citizens and relevantly qualified professionals presumed to be free of conflicts of interest, and, if the agency provides direct services, individuals served by the agency and/or their representatives.

____4.10.1.8* The agency is administered and operated in accordance with effective management principles.

____4.10.1.8.1* The agency has a current table of organization that shows the governance and administrative pattern of the agency.

____4.10.1.8.1.1* The agency's table of organization shows the major operating programs of the agency, with staff divisions, the administrative personnel in charge of the programs and divisions, and their lines of authority, responsibility, and communication.

____4.10.1.8.1.2 The administrative organization of the agency is appropriate to the program needs of the individuals served.

____4.10.1.8.2 The agency's organization provides for the judicious delegation of administrative authority and responsibility among qualified members of the staff, in order to distribute the administrative load of the agency and to facilitate its operating efficiency.

____4.10.1.8.2.1 The agency's organization provides for the utilization of staff with different levels of training by using those with more training to supervise and teach those with less training.

____4.10.1.8.2.2* The agency's organization is such that problems requiring ongoing decision making regarding the welfare of the individuals served are handled primarily by personnel on the lowest level competent to resolve the problem.

____4.10.1.8.3 The agency's organization provides effective channels of communication in all directions.

____4.10.1.9* The agency provides for effective participation of, and communication with, staff and individuals served. Such participation and communication are provided in the following ways:

____4.10.1.9.1* agency staff meetings are held regularly;

____4.10.1.9.2* standing committees appropriate to the agency (such as records, safety, human rights, utilization review, research review, pharmacy and therapeutics, and infection and sanitation committees) meet regularly;

____4.10.1.9.3* agency committees include the participation of direct-contact staff, whenever appropriate;

____4.10.1.9.4* committees include participation of individuals served, whenever appropriate;

____4.10.1.9.5* minutes and reports of agency staff meetings and of standing and ad hoc committee meetings, including records of recommendations and their implementation, are kept and filed;

____4.10.1.9.6* summaries of the minutes and reports of agency staff and committee meetings are distributed to participants and to appropriate staff members; and

____4.10.1.9.7 summaries of the minutes and reports of agency governing board meetings are distributed to staff and to consumer representatives.

____4.10.1.10* Various forms of communication (such as meetings, minutes of meetings, directives, and bulletins) are utilized to foster understanding among the staff, among individuals served, between staff and individuals served, and between agency, family, and community.

____4.10.1.11* The agency has copies of the laws, rules, and regulations that are relevant to its function.

____4.10.1.12* The agency has a policies and procedures manual that describes the current methods, forms, and processes that are utilized to achieve its goals and objectives. These policies and procedures are:

____4.10.1.12.1* consistent with the needs of the individuals served by the agency;

____4.10.1.12.2* consistent with the agency's philosophy and objectives;

____4.10.1.12.3 consistent with currently accepted theories, principles, and goals;

____4.10.1.12.4 consistent with the resources available;

____4.10.1.12.5 applicable to all areas of service provided;

____4.10.1.12.6 prepared by relevant personnel;

____4.10.1.12.7 reviewed periodically, but at least annually, by relevant personnel;

____4.10.1.12.8* in compliance with applicable laws and regulations; and

____4.10.1.12.9 available to, and adhered to by, all concerned.

____4.10.1.13* The agency has implemented a plan for a continuing audit of management structure and effectiveness. The audit addresses:

____4.10.1.13.1* implementation of the agency's stated policies and procedures, and

____4.10.1.13.2* compliance of the agency's policies and procedures with laws and regulations.

____4.10.1.13.3* Audit results and consequent modifications to be made are recorded.

____4.10.1.14* Each program component of the agency is licensed, certified, or approved, as required by the appropriate state agency.

____4.10.1.15* The agency's fund raising activities comply with local and state laws and with applicable ethical practices, such as those of the National Society of Fund Raisers.

____4.10.1.16* Adequate administrative support services (which may include, but need not be limited to, clerical, communication, dietary, financial, housekeeping, laundry, personnel, physical plant, records, safety and security, and supply and purchasing services) are provided to efficiently meet the needs of, and contribute to, program services, and to facilitate attainment of the goals and objectives of the agency.

____4.10.1.16.1 Administrative support services are directed by a qualified administrator, trained and experienced to provide skilled and efficient coordination of these services. (In larger agencies, provision may be made for both executive direction and administration of support services; in smaller agencies, a single person may fulfill both functions.)

____4.10.1.16.1.1 The administrator of administrative support services has at least a baccalaureate degree and three years of experience in a responsible and relevant administrative position, or has completed formal graduate education in health or human services administration, or its equivalent.

____4.10.1.16.2 All administrative support services personnel have sufficient understanding and appreciation of developmental disabilities to assure that each employee's work and relationships with the individuals served contribute positively to their welfare.

____4.10.1.16.3* There is adequate communication service, including adequate telephone service. The communication system assures:

____4.10.1.16.3.1* prompt contact of on-duty personnel, and

____4.10.1.16.3.2* prompt notification of responsible personnel in the event of an emergency.

4.10.2 Fiscal Affairs

Standards pertaining to all agencies

____4.10.2.1* The agency's funds are budgeted and spent in accordance with the principles and procedures of either program budgeting or another nationally recognized budgeting procedure.

____4.10.2.1.1 Budget preparation is the product of team management, which includes active participation of professional staff.

____4.10.2.1.2 Agency budget performance reports are prepared at appropriate intervals and submitted to those agency staff and governing board members who participate in budget and management responsibilities.

____4.10.2.1.3 The agency has provisions for rebudgeting of funds in accordance with changing programs needs.

____4.10.2.2 The budget requests submitted by the agency are documented and interpreted.

____4.10.2.2.1* The budget requests submitted by the agency reflect its program needs, as determined by its staff.

____4.10.2.2.1.1 The fixed and incremental costs of adequate programming for individuals are recorded.

____4.10.2.2.2 The agency's budget requests reflect evaluation of its performance regarding unmet objectives.

____4.10.2.2.3 The agency's budget requests reflect the unmet needs of all who need service.

4.10.2.3 The agency earmarks a percentage of its operating budget for self-renewal purposes, such as:

____4.10.2.3.1 development of operational data records;

____4.10.2.3.2 research on its own programs;

____4.10.2.3.3* evaluation by qualified persons who are not part of the agency;

____4.10.2.3.4 elicitation of feedback from consumers of the agency's services or from their representatives; and

____4.10.2.3.5* staff training.

4.10.2.3.6 The findings generated by the agency's self-renewal activities are provided:

____4.10.2.3.6.1 to all members of the agency's staff; and

____4.10.2.3.6.2 to consumer representatives, upon request.

____4.10.2.4 Persons acting on the agency's budget requests (such as board members, state budget officials, and members of appropriations committees) have firsthand knowledge of its operation and needs, obtained by regular visitation and observation of its programs.

____4.10.2.5* There is a formal system of internal control for handling the agency's fiscal affairs.

____4.10.2.5.1* The agency has an adequate responsibility-accounting system, that is, a system that provides for the accumulation and communication of data relating to revenues, expenses, and volume of services rendered, classified according to the organizational units producing the revenues and responsible for incurring the expenses.

____4.10.2.5.2* A full audit of the agency's fiscal activities is performed annually by a certified public accountant independent of the agency, or as otherwise provided by law.

____4.10.2.5.2.1 Recommendations in the audit's management letter are implemented.

____4.10.2.5.3* Fiscal reports are prepared annually and are available to the agency's public.

____4.10.2.5.4 Where the size of the agency's operation warrants a fiscal officer, the officer has appropriate training and experience in accounting and auditing.

____4.10.2.6* The agency has written policies regarding authorizations and approvals for purchasing supplies, services, and equipment.

____4.10.2.6.1* There is adequate documentation of the agency's purchasing process, including, where appropriate, requisitions, bids from a number of suppliers, purchase orders, and receiving reports.

4.10.2.6.2 The agency's inventory control system and stockroom operation are adequate with respect to:

____4.10.2.6.2.1 receiving supplies,

____4.10.2.6.2.2 issuing supplies as needed in programs,

____4.10.2.6.2.3 maintaining necessary stock level, and

____4.10.2.6.2.4 establishing responsibility for stocks.

____4.10.2.6.3* The agency's purchasing system is responsive to programmatic needs and secures approved requests within established time frames.

____4.10.2.6.4 Where the size of the agency's operation warrants, the person responsible for directing purchase, supply, and property control has had several years of progressively more responsible experience in these fields, or has had comparable training.

____4.10.2.7* Unless otherwise provided by law, the agency has insurance that includes, but is not necessarily limited to, insurance against public and professional liability, fire, theft, and disaster.

____4.10.2.8* If the agency charges for its services, a written schedule of its rates and charge policies is available to any person upon request.

4.10.3 Personnel Policies

Standards pertaining to all agencies

____4.10.3.1* Adequate services for personnel administration are provided by means appropriate to the size and function of the agency.

____4.10.3.1.1 The agency's personnel director (if the agency's size warrants such a position) has had several years of progressively more responsible training and/or experience in personnel administration, and has demonstrated competence in this area.

____4.10.3.2* The agency has a statement of its personnel policies and practices.

____4.10.3.2.1* A statement of the agency's personnel policies and practices is provided to each employee.

____4.10.3.3* The employment, assignment, and promotion of agency personnel is based on their qualifications and abilities, without regard to sex, color, creed, age, disability not relevant to job performance, marital status, ethnic or national origin, or membership in an organization.

____4.10.3.4* All applicants for agency positions are initially screened to determine if they are capable of fulfilling specific job requirements.

____4.10.3.4.1 All agency personnel undergo a physical examination at the time of employment.

____4.10.3.5* Written policies assure that employees with infectious diseases are assigned to areas that will reduce the possibility of transmission of disease.

____4.10.3.6 All employees are appointed for a limited probationary period, in order to determine if they are capable of fulfilling the specific requirements of their jobs.

____4.10.3.7* Each agency employee is evaluated at least annually after the initial probationary period. The evaluation is:

____4.10.3.7.1* reviewed with the employee, and

____4.10.3.7.2* recorded in the employee's personnel record.

____4.10.3.8* The agency has an authorized procedure, consistent with due process, for suspension or dismissal of an employee for cause.

____4.10.3.9* The agency develops a job description with each consultant and staff member. Each job description includes, but is not necessarily limited to:

____4.10.3.9.1 a description of the person's duties and responsibilities; and

____4.10.3.9.2 the person's role, if any, in implementing individual program plans.

____4.10.3.9.3 Each job description is reviewed at least annually.

____4.10.3.10 The agency utilizes a performance appraisal system. The system includes:

____4.10.3.10.1 a statement of each staff member's accountability for accomplishing mutually determined objectives;

____4.10.3.10.2 outcome measures to evaluate the staff member's performance;

____4.10.3.10.3 specified performance evaluation techniques; and

____4.10.3.10.4 a signed performance description agreement between the agency and the staff member.

4.10.3.11 Methods of improving the welfare and security of agency employees include:

____4.10.3.11.1 a merit system or its equivalent;

____4.10.3.11.2* a salary range scale covering all positions, which is available upon request;

____4.10.3.11.3 effective grievance procedures;

____4.10.3.11.4* provisions for vacations, holidays, and sick leave;

____4.10.3.11.5 provisions for health insurance and retirement;

____4.10.3.11.6 permitting employee organizations;

____4.10.3.11.7 opportunities for continuing educational experiences, including educational leave;

____4.10.3.11.8 career ladders; and

____4.10.3.11.9 provisions for recognizing outstanding contributions to the agency.

4.10.3.12 The agency:

____4.10.3.12.1* conducts exit interviews,

____4.10.3.12.2* maintains information concerning the reasons for separation of employees, and

____4.10.3.12.3 reviews such information at least annually.

4.10.4 Documentation

Definition

Documentation refers to the maintenance of a records system that maintains records concerning all individuals served (see also Section 3.1), in addition to those records required for individual program planning and implementation (see Section 1.6).

Principles

In order to effectively plan, manage, and evaluate its services, the agency must maintain information concerning the identification and characteristics of the individuals served, as well as those functional records that are essential for individual program planning and implementation. The agency should also document contacts with individuals who were referred to other agencies.

A main or "unit" record, containing information pertinent to the individual and the individual's program plan, should be maintained for each individual. A centralized or decentralized records system may be employed. In a centralized system, unit records are kept at a central location. In a decentralized system, unit records are maintained at primary programming sites, such as living units or program areas.

The agency's records system should be designed to prevent duplication of data collection efforts. With appropriate authorization, information collected by one agency should be shared with other agencies. Where a community or state format for a records system is established, the agency's system should be compatible. If there is no community or state format, the agency should be actively engaged in trying to establish a unified system.

Litigation concerning an individual invariably involves a review of the individual's record, and legal decisions are frequently based on the information recorded therein. Recent litigation has held that the record developed by a practitioner or agency is the property of the individual served. Under the principle of the right to know, the record must be available to the individual and, as appropriate, to the individual's family, upon request, in accordance with applicable law. An agency staff member may withhold specific material that is in the individual's record, in accordance with the concept of privileged information. However, the individual must be told what material is being withheld, and the right to a fair hearing must always be observed. When the record is made available to the individual or the individual's family, a staff member should be present to interpret it to them.

Standards pertaining to all agencies

____4.10.4.1* A main or "unit" record that contains all pertinent information, as described in these *Standards*, is maintained for each individual served by the agency.

4.10.4.2 The following information is obtained and entered in the individual's record either at the time of entry or prior to enrollment, as appropriate:

____4.10.4.2.1* the individual's name, address, and telephone number; date of entry; place and date of birth; marital status; and, unless prohibited by law, social security number;

____4.10.4.2.2* sex, race, height, weight, color of hair, color of eyes, identifying marks, and recent photograph;

____4.10.4.2.3* name, address, and telephone number of parents, guardian, advocate, and/or next of kin;

____4.10.4.2.4* mother's maiden name, birthplaces and birthdates of parents, and parents' marital status;

____4.10.4.2.5* reason for entry, referral, or other disposition;

____4.10.4.2.6* legal competency status;

____4.10.4.2.7* language(s) spoken or understood, and language(s) used in the individual's home environment;

____4.10.4.2.8* sources of support, including social security, veteran's benefits, and insurance;

____4.10.4.2.9 provisions for clothing and other personal needs;

____4.10.4.2.10* information relevant to religious preference;

____4.10.4.2.11* reports of previous histories, evaluations, or observations;

____4.10.4.2.12* age at onset of disability;

____4.10.4.2.13* name, address, and telephone number of physician or health facility providing medical care;

____4.10.4.2.14* medication history;

____4.10.4.2.15* allergies; and

____4.10.4.2.16* type and legal status of admission to a residential program.

____4.10.4.3* Information recorded in the individual's record at the times of entry and enrollment is updated periodically.

____4.10.4.4* The individual's record includes a diagnosis based on the American Association on Mental Deficiency's (AAMD) *Manual on Terminology and Classification in Mental Retardation*, 1977 revision, the *Diagnostic and Statistical Manual of Mental Disorders*, Second Edition (DSM-II), published by the American Psychiatric Association, or another appropriate, accepted, and current standard nomenclature.

____4.10.4.5* Symbols and abbreviations used by the agency are in a list approved by the agency's chief executive officer, and a legend understood by the staff is provided to explain them.

____4.10.4.5.1 Diagnoses are recorded in full, without the use of symbols or abbreviations.

____4.10.4.6* A periodic, at least annual, review of the content of the records is made. Such a review is made:

____4.10.4.6.1 by record personnel to assure that records are current, accurate, and complete; and

____4.10.4.6.2 by a committee of appropriate staff, including the person responsible for supervising the agency's record system, to assure that they meet the standards set forth herein.

____4.10.4.7* The agency has a continuing system for collecting and recording accurate data that describe the individuals served and that are in such form as to permit data retrieval and usage for description, programming of services, and research. While the type and amount of statistical information depends upon the agency's particular needs, such information includes at least the following:

____4.10.4.7.1 number of individuals served by age group, sex, race, and place of residence;

____4.10.4.7.2 number of individuals served by level of retardation, classified according to the *AAMD Manual*, 1977 revision;

____4.10.4.7.3 number of individuals served by level of adaptive behavior, classified according to the *AAMD Manual*, 1977 revision;

____4.10.4.7.4 number of individuals served with specified physical disabilities;

____4.10.4.7.5 number of individuals served who are ambulatory, mobile nonambulatory, and nonmobile;

____4.10.4.7.6 number of individuals served with sensory defects;

____4.10.4.7.7 number of individuals served with communication handicaps;

____4.10.4.7.8 number of individuals served with seizure disorders;

____4.10.4.7.9 number of individuals served with emotional and behavioral problems;

____4.10.4.7.10 number of individuals served by etiological diagnoses, classified according to the *AAMD Manual*, 1977 revision; the *Diagnostic and Statistical Manual of Mental Disorders*, Second Edition, or another appropriate, accepted, and current standard nomenclature;

____4.10.4.7.11 number of individuals served by movement into, out of, and within the agency; and

____4.10.4.7.12 number of individuals served by length of service to individuals.

____4.10.4.7.13* Statistical data concerning individuals served are reported, as required, to appropriate community, state, and federal agencies.

____4.10.4.8* The agency maintains an organized record service for the collection and dissemination of information regarding individuals served. (A centralized or decentralized system of record keeping may be used, in accordance with the needs of the agency.)

____4.10.4.8.1* Individuals' records are readily accessible to authorized personnel.

____4.10.4.8.2 The agency's record system is compatible with an existing community or state system.

____4.10.4.8.3* The agency maintains a master index of all individuals served.

____4.10.4.8.4* Individuals' records are retained for the period of time specified by the agency, but at least for the period of time required by the laws of the state in which the agency is located.

____4.10.4.8.5* The agency's record system is supervised on a full-time or part-time basis, according to the needs of the agency, by a person who is either a Registered Record Administrator or an Accredited Record Technician, or by a person who otherwise has demonstrated competence and experience in administering and supervising the maintenance and use of records and reports.

4.11 Program Evaluation

Definition

Program evaluation is a process that measures program outcomes against the previously stated goals and objectives of the agency.

Principles

The purpose of standards is to assure that services of high quality are provided, and compliance with valid standards is important for that reason. The quality of an agency's services, however, cannot be measured solely by its compliance with standards. Quality can be measured only by comparing the results of efforts with their goals and objectives. While the standards provide some objectives, the ultimate goals of an agency serving developmentally disabled individuals are attained only as the agency helps such individuals to achieve specified objectives in their lives.

To provide assurance of its concern with maintaining and improving the quality of its services, therefore, each agency must demonstrate that it has effective methods for comparing outcomes with goals, that it periodically evaluates its performance against its stated goals and objectives, and that it coordinates ongoing program evaluation with a built-in mechanism for the consequent review and modification of agency operations. The effectiveness of an agency that has responsibility for planning or implementing individual program plans must be measured in terms of the progress of individuals served toward the objectives that are specified in their individual program plans.

Where cooperative efforts among agencies are designed to achieve a common goal, services must be evaluated cooperatively and in relation to one another. Funding agencies must evaluate their practices to assure maximum efficiency for the benefit of the service agencies that are funded and for the ultimate benefit of the developmentally disabled individuals that those agencies serve. The service delivery system must be evaluated in terms of the availability of services to meet identified needs, and in terms of the degree to which the needs of the population have been identified. All evaluation processes must be coordinated with built-in mechanisms for the consequent review and modification of objectives, policies, and practices.

Standards pertaining to all agencies

____4.11.1* The agency periodically, and at least annually, evaluates its performance against its stated goals and objectives. The evaluation includes, but is not necessarily limited to, assessment of:

  ____4.11.1.1 the agency's objectives,

  ____4.11.1.2 the relation of the agency's objectives to the objectives specified in the individual program plans of individuals served,

  ____4.11.1.3 agency program standards,

  ____4.11.1.4 program methodologies,

  ____4.11.1.5 staff performance,

  ____4.11.1.6 staffing requirements, and

  ____4.11.1.7 space requirements.

4.11.2 The agency's program evaluation procedures specify:

- ____4.11.2.1 who is responsible for conducting the evaluation,
- ____4.11.2.2 what data are to be collected,
- ____4.11.2.3 when data are to be collected, and
- ____4.11.2.4 how the data are to be analyzed.

____4.11.3* The agency measures the effectiveness of its programs and services in terms of the progress of individuals served toward the objectives specified in their individual program plans.

____4.11.4 The agency provides for staff involvement in its program evaluation process, and provides for services to individuals to be evaluated by staff who are professionally competent to do so.

____4.11.5* The agency provides for the involvement of individuals served and their families in its program evaluation process.

____4.11.6 The agency provides for periodic, external peer review, or assessment by an advisory committee of individuals served, of agency practices and services, including services provided by other agencies that support those provided by the agency itself.

____4.11.7 The agency's evaluation process has built-in mechanisms for the consequent review and modification of objectives, policies, and practices.

- ____4.11.7.1 Evaluation results and consequent modification plans are recorded.

____4.11.8 Where cooperative efforts among agencies are designed to achieve a common goal, services are evaluated cooperatively and in relation to one another.

____4.11.9 The agency provides its funding sources with qualitative evidence of accomplishments and shortcomings in relation to its stated goals and objectives.

- ____4.11.9.1 The agency documents its efforts to facilitate maximum coordination among its funding sources with respect to licensing requirements, required reports, accountability requirements, and time lags between approvals and receipts of funds.

4.12 Provision and Maintenance of Facilities and Equipment

Definition

Provision and maintenance of facilities and equipment refers to the provision of all those physical environmental resources that are necessary for providing adequate services.

Standards pertaining to all agencies

____4.12.1* The agency provides the space, facilities, equipment, resources, and environment that are appropriate and adequate for conducting its programs in accordance with the standards specified in this document.

____4.12.1.1* Physical settings, including furnishings and decorations, are appropriate to the chronological ages of the individuals served.

____4.12.1.2* Temperature and humidity are maintained within a normal comfort range.

____4.12.1.3 Facilities for conducting confidential interviews are provided as required.

____4.12.2* Toilet facilities that are equipped in accordance with the needs of the individuals served, and that provide for individual privacy, are readily accessible.

____4.12.2.1* Each toilet is equipped with a seat.

____4.12.2.2* Toilet tissue is readily accessible at each toilet.

____4.12.3* Each program and residence unit provides a means of obtaining a drink of water that is usable by the individuals served therein.

____4.12.4* Dining areas provide a pleasant and normalizing environment that is attractively furnished and decorated, and that is of good acoustical quality.

____4.12.5 Consultation in planning, designing, modifying, and equipping the agency's professional service facilities is provided by qualified practitioners in the professional service areas.

____4.12.6* The agency has an appropriate, written preventive maintenance program.

____4.12.6.1 Where the size of the agency warrants, engineering and maintenance are directed by an engineer who has had at least three years of progressively more responsible experience in institutional engineering and maintenance.

4.12.7 As appropriate to the size and nature of the agency, the person responsible for directing housekeeping services has had:

____4.12.7.1 several years of progressively more responsible experience in this field, and/or related training;

____4.12.7.2 formal training in courses or vocational schools; and

____4.12.7.3 experience and training in supervision and management.

4.12.8 Laundry services are managed so that:

____4.12.8.1* daily clothing and linen needs are met without delay, and

____4.12.8.2* there is minimum loss and damage to clothing.

4.12.8.3 As appropriate to the size and nature of the agency, the person responsible for directing laundry services:

____4.12.8.3.1 has had several years of progressively more responsible experience in this field, and/or related training; and

____4.12.8.3.2 has the ability to supervise individuals who work in the laundry.

Section 5
Safety and Sanitation

Principles

The agency's premises, in addition to being as normalized as possible, must be safe and sanitary. Consequently, the agency must comply with the fire safety, sanitation, health, and environmental safety codes and regulations of the state or local authorities that have primary jurisdiction over it in these matters.

Prior to survey, an agency must provide documentary evidence that it is in compliance with the applicable provisions of the 1973 edition of the *Life Safety Code* of the National Fire Protection Association. Compliance with the "Institutional Occupancies" section of the *Code* is required only for residential buildings that contain more than fifteen beds and that house residents who are incapable of taking action for self-preservation. The "Residential Occupancies" section of the *Code* may be applied to other residential buildings if there are procedures that assure the orderly evacuation of any resident who is incapable of taking action for self-preservation.

Each agency must have a plan for effectively meeting potential emergencies, including an evacuation plan that is rehearsed at specified intervals. Provisions for handling drugs must assure the safety of the individuals served.

Standards pertaining to all agencies

____5.1* Applicable requirements of the National Fire Protection Association's *Life Safety Code*, 1973 edition, are met in all buildings utilized by the agency.

____5.2* The agency has records that document its compliance with the regulations of the state or local fire safety authority that has primary jurisdiction over it.

____5.2.1* The agency has records and reports of periodic fire safety inspections.

____5.3* The agency has a written staff organization plan and written procedures, which are communicated to the staff and reviewed annually by the staff, for meeting all potential emergencies and disasters, such as fire, severe weather, and missing persons.

5.3.1 Plans and procedures for meeting potential emergencies and disasters include:

____5.3.1.1* the assignment of personnel to specific tasks and responsibilities,

____5.3.1.2* instructions relating to the use of alarm systems and signals,

____5.3.1.3* information concerning methods of fire containment,

____5.3.1.4* systems for notification of appropriate persons, ____5.3.1.5* the location of fire-fighting equipment, and

____5.3.1.6* specification of evacuation routes and procedures.

____5.3.2* Evacuation routes and other emergency procedures, as appropriate to the agency, are posted at suitable locations throughout the agency.

____5.3.3* Evacuation drills are held at least quarterly for each shift of agency personnel and under varied conditions. Such drills are held in order to:

____5.3.3.1* assure that all personnel on all shifts are trained to perform assigned tasks,

____5.3.3.2* assure that all personnel on all shifts are familiar with the use of the agency's fire-fighting equipment, and

____5.3.3.3 evaluate the effectiveness of disaster plans and procedures.

____5.3.3.4* During at least one drill each year on each shift, individuals are actually evacuated to safe areas, unless the health or safety of the individuals would be endangered thereby.

____5.3.3.4.1 Where the welfare of the individuals precludes an actual evacuation of an entire building, drills are held in which successive portions of the building are evacuated under conditions that assure the capability of evacuating the entire building with personnel usually available, should the need arise.

____5.3.3.4.2* Special provisions, such as fire chutes and mattress loops with poles, are available for evacuating physically handicapped individuals.

____5.3.3.5* A written, filed report and evaluation of each evacuation drill indicates whether the evacuation plan was realized, whether any problems were encountered, and whether any corrections are needed.

____5.4* The agency has records that document its compliance with the sanitation, health, and environmental safety codes of the state or local authority having primary jurisdiction over it in these matters.

____5.4.1* An active safety program is maintained by a multidisciplinary safety committee that investigates all accidents and makes recommendations for prevention.

____5.4.1.1* Records of the activities of the safety committee are kept.

____5.4.2* Active attention is directed to avoiding hazards to the individuals being served, including, but not limited to, the accessibility of dangerous substances, sharp objects, and unprotected electrical outlets.

____5.4.3* The type of glass or other glazing material used is appropriate to the safety of the individuals served.

____5.4.4* Floors and stairs provide a clean, nonabrasive, slip-resistant, and safe surface.

____5.4.5* Heating apparatus does not constitute a burn hazard to the individuals served.

____5.4.6* The temperature of the hot water at all taps to which individuals have access is controlled by the use of thermostatically controlled mixing valves or by other means (including control at the source), so that it does not exceed 110 degrees Fahrenheit, unless such control is contrary to the program goals of the individuals served.

____5.4.6.1 When used, mixing valves are equipped with safety alarms that provide both auditory and visual signals of valve failure.

____5.4.7* There are adequate safety shields on the moving parts of all dumb waiters, elevators, lawn mowers, and other machinery, as provided for in applicable standards and codes.

____5.4.8* The agency maintains records of occupational injuries and illnesses, as required by the Occupational Safety and Health Act of 1970.

____5.4.9 The agency keeps written inspection reports and records from insurance companies on file.

____5.5* Written reports of inspections by state or local health authorities, and records of action taken on their recommendations, are kept on file at the agency.

____5.5.1* The agency's premises are sanitary and free of offensive odors.

5.5.2 Dining areas and facilities, and procedures for storage, preparation, and distribution of food are:

____5.5.2.1* in compliance with applicable state and local sanitation and other requirements; and

____5.5.2.2* adequate for sanitary storage of all food, dishes, and equipment.

____5.5.2.3* Any person who is afflicted with a disease in a communicable stage, or who is a carrier of a communicable disease, or who has an open wound is not permitted to work in any food service operation.

____5.5.2.4 Cups used for drinking water are either properly washed after each use or they are used once and disposed of.

____5.5.2.5 Dining areas are equipped with tables having smooth, impervious tops (clean table coverings may be used).

____5.5.2.6* Dry or staple food items are stored at least four inches above the floor in a ventilated room that is not subject to sewage or waste water backflow, or to contamination by condensation, leakage, rodents, or vermin.

____5.5.2.7* Perishable foods are stored at the proper temperatures to preserve nutritive values.

____5.5.2.8* When food is transported, proper temperature is maintained, food is protected from contamination and spoilage, and nutritive value is preserved.

____5.5.2.9* Food served to an individual and not consumed is discarded.

____5.5.2.10* Effective procedures for cleaning all equipment and work areas are used consistently.

____5.5.2.10.1* Dishwashing and panwashing is carried out in compliance with state and local health codes.

____5.5.3* Waste and garbage are held, transferred, and disposed of in a manner that does not create a nuisance, permit the transmission of disease, nor create a breeding place for insects or rodents.

5.5.3.1 Waste that is not disposed of by mechanical means is:

____5.5.3.1.1 kept in leakproof, nonabsorbent containers with close-fitting covers; and

____5.5.3.1.2 disposed of daily.

5.5.3.2 Waste containers are:

____5.5.3.2.1 provided with impervious plastic liners; and

____5.5.3.2.2 thoroughly cleaned, inside and out, each time they are emptied.

____5.5.4* Handwashing facilities are available in, or immediately adjacent to, all rest rooms, kitchens, food serving areas, sleeping rooms, and treatment rooms.

____5.5.5* The agency's buildings are free of insects, rodents, and vermin.

____5.6* Drugs are stored under proper conditions of sanitation, temperature, light, moisture, ventilation, segregation, and security.

____5.6.1* The security requirements of federal and state laws concerning drugs are satisfied wherever drugs are kept, including storerooms, pharmacies, treatment rooms, and living units.

____5.6.2* All drugs are kept under lock and key except when authorized personnel are in attendance.

____5.6.3* Poisons, drugs used externally, and drugs taken internally are stored on separate shelves or in separate cabinets.

____5.6.4* Medications stored in a refrigerator containing things other than drugs are kept in a separate compartment and proper security is maintained.

5.6.5 Drug preparation areas are:

____5.6.5.1* properly secured,

____5.6.5.2* well lighted, and

____5.6.5.3* located where personnel will not be interrupted when handling drugs.

____5.6.6 Drugs in each living unit are reviewed monthly, and outdated and deteriorated drugs and drugs not being used are removed.

____5.6.7* Discontinued and outdated drugs, and containers with worn, illegible, or missing labels, are either returned to the pharmacy for proper disposition or otherwise disposed of in a safe manner.

____5.7* The agency uses lead-free paint.

____5.7.1* Oil paint and plaster containing lead have been either removed or covered in such a manner that they are not accessible.

____5.8* Appropriate provisions are made for emergency auxiliary heat in living units by means of alternate sources of electric power, alternate fuels, stand-by equipment, and/or arrangements with other agencies.

Section 6
Research and Research Utilization

Definitions

Research is a systematic and detailed attempt to discover or confirm facts relating to the problems associated with developmental disabilities. Research utilization includes the dissemination of research findings and the use of such findings to improve services for developmentally disabled individuals.

Principles

Because the understanding, prevention, and amelioration of developmental disabilities ultimately depends upon knowledge gained through research, the administration and staff of the agency and, in the case of public agencies, the appropriate governmental unit, should encourage research activity. The agency's statement of purpose should indicate if research is to be an agency activity. If the agency engages in research activity, it must:

- have a written policy concerning the conduct of research,
- protect the rights of research subjects,
- assure adherence to ethical standards in the conduct of research,
- disseminate the findings of research that is conducted by its staff, or that involves its services or individuals served, and
- use such findings to improve its own operations whenever possible.

Standards pertaining to all agencies

____6.1* The agency's statement of purpose indicates whether or not it will engage in research activities.

____6.2 The agency has a mechanism to review research findings external to the agency, and to implement those findings that will improve the quality of services provided.

Standards pertaining only to agencies engaging in research activities

____6.3* The agency has a written policy concerning the purpose and conduct of all research involving the agency's staff, services, or individuals served.

____6.3.1* Agency staff members are consulted regarding the development of research efforts in their areas of competence and interest.

____6.3.2 Each person conducting research involving human subjects is affiliated with, or sponsored by, an agency that can and does share responsibility for the protection of the subjects involved.

____6.3.3* The agency has guidelines to deal with any emergency that may develop, even in the course of seemingly routine research activities.

____6.3.4 Opportunities and resources to conduct research are made available to members of the staff who wish to conduct applied and/or basic research, and are competent to do so.

____6.3.4.1 Research resources and/or necessary research assistance are made available to all staff members who have identified researchable problems related to the programs for which they are responsible.

____6.3.4.2 Staff members cooperate in interdisciplinary research.

____6.4 Research by qualified investigators who are not staff members of the agency is encouraged.

____6.4.1* A staff member is assigned to provide liaison with each research project conducted by outside investigators.

____6.5 The agency cooperates with research and research training programs that are conducted by colleges, universities, and research agencies, or by other qualified investigators.

____6.6* The agency has an interdisciplinary research committee that includes both qualified agency staff members and qualified persons who are not members of the agency's staff.

____6.6.1 Each member of the agency's interdisciplinary research committee is qualified by training and experience to conduct initial and continuing reviews of research projects.

6.6.2 The agency's interdisciplinary research committee reviews all proposed research to assure:

____6.6.2.1 adequacy of research design,

____6.6.2.2* implementation of ethical standards in the design, and

____6.6.2.3* compliance with the provisions of federal laws and regulations.

____6.6.3 The agency's interdisciplinary research committee maintains a continuing review of all research activity.

6.7 The agency's human rights committee assures:

____6.7.1* that the rights and welfare of research subjects are protected;

____6.7.2* that consent to participation in research is obtained by adequate and appropriate methods; and

____6.7.3* that individuals served are not used as a captive source of research subjects for purposes unrelated to their specific welfare, unless they or their families have agreed to the research, and the research is in no way detrimental to their welfare.

6.8 Procedures for obtaining consent include:

____6.8.1* an explanation of the procedures to be followed, including an identification of those that are experimental, ____6.8.2* a description of the attendant discomforts and risks,

____6.8.3* a description of the benefits to be expected,

____6.8.4* a disclosure of appropriate alternative procedures that would be advantageous for the subject,

____6.8.5* an offer to answer any inquiries concerning the procedures, and

____6.8.6* a statement to the subject that he or she is free to withdraw his or her consent and to discontinue participation in the project or activity at any time.

____6.8.7* The written or oral agreement entered into by the subject contains no exculpatory language that could be interpreted to mean that the subject waives any of his or her legal rights, or releases the agency or its agents from liability for negligence.

____6.8.8* Methods for obtaining consent to participation in research are reviewed at least annually.

6.9 Investigators and others directly involved in research:

____6.9.1* adhere to the ethical standards of their professions concerning the conduct of research; and

____6.9.2* obtain consent from each subject, or have access to the record of consent.

____6.10 The principal investigator of each completed research project is responsible for communicating to the staff of the agency the purpose, nature, outcome, and possible practical or theoretical implications of the research.

____6.10.1* Outside researchers have the same obligations relative to staff information and feedback as do agency staff members.

____6.10.2 Copies of reports resulting from research projects are maintained in the agency.

____6.10.3 The agency assists in disseminating the results of its research to other units of the service delivery system.

Section 7

The Agency in the Service Delivery System

Definition

The service delivery system is the network of specialized and generic service components that is directed toward meeting the general and extraordinary needs of the developmentally disabled individuals in the population served.

Principles

The service delivery system must function as a mediator between the developmentally disabled individual and his or her cultural environment, mitigating against and compensating for the abnormalizing effects of disability. The system performs this function by improving the individual's ability to provide for herself or himself, and by modifying the environment to bridge gaps between personal resources and the normal fulfillment of need.

To be an effective mediator, the service delivery system should be so organized that readily accessible services are available to developmentally disabled individuals when they need them. Consequently, the delivery of services must be systematically coordinated both within each agency and among all agencies in the system. Each agency that supplies one or more service components should publish a clear statement of the extent and limitations of the service or services that it contributes to the total system. Each agency must also demonstrate a willingness to modify its services in relation to individual and family needs, in relation to other services, and in response to community planning processes. While each agency should not be expected to provide all services needed by developmentally disabled individuals and their families, every agency should know where such services are obtainable, and should document its efforts to make all such services available within the community.

One agency in the service delivery system should be responsible for implementing a systematic method of collecting data useful for planning and coordinating activities. This agency should provide other agencies with up-to-date information on available community resources for serving developmentally disabled individuals. Community education should be an ongoing program, reflecting cooperation among agencies. Each agency should be aware of the existing components of the prevention program, and should engage in efforts to implement a total prevention program. Each agency should assume responsibility for assuring an adequate present and future supply of qualified personnel to provide services to disabled individuals.

Because living is such a complex process of interactions, the delivery of assistive, supportive, and protective services requires a complex, interactive system. To the extent that service elements remain separate and uncoordinated, they tend to fragmentize and lose effectiveness. Systems of service delivery will doubtlessly always fall short of ideal coherence, but, to the degree that they are directed toward normalization, they exhibit certain indispensible characteristics, which are reflected in the operation of an individual agency. These characteristics concern responsiveness; availability, which includes comprehensiveness, completeness, and balance; accessibility; individualization, which includes acceptability and participation; documentation; quality control; and accountability.

Responsiveness

In order to design a service delivery system that is responsive to the unique needs of the community it serves, the target population must be identified and the parameters of need must be determined. Consequently, demographic analysis should include a full account not only of the target population, but also of the resources of the community relevant to the conditions of disability. However, it must be remembered that the needs of individuals change with the advancement of knowledge, the evolution of social life, and the changing aspirations of people. The service delivery system must be responsive to these changes, otherwise it will fall back into sterile habits of institutional self-perpetuation that serve no one but the agencies themselves.

Throughout an effective service delivery system, every component agency must be able to respond to any individual appeal, either by initiating direct service itself, or by referring to an appropriate source and systematically following-up to see that the problem is solved. In addition, the service delivery system, as a whole and in all its parts, must reach out to meet expressed or unexpressed needs. Case finding to serve the needs of inarticulate individuals must not be deferred by a reluctance to face the true magnitude of the community's problems.

Particular emphasis should be placed on early detection. Parents, teachers, nurses, obstetricians, pediatricians, family physicians, maternity clinics, hospitals, and health departments should be alerted to the urgency of prompt recognition of delayed maturation and other developmental anomalies, and of early referral to appropriate agencies staffed to serve infants and their families.

An individual agency must be measured against the criteria of the total service delivery system's responsiveness to community needs, and by its own ability to respond to the needs of individuals, whether voiced or silent.

Availability

The ultimate goal of the system should be to make available within the community all of the services necessary to meet the needs of the developmentally disabled population. Such a goal is difficult to attain, and its achievement requires a process of evolution. The process should be one in which carefully defined, time-limited objectives are progressively translated into concrete operations. Expressions of good will and intent, plans for development, enabling legislation, tables of organization, even buildings, staffs, and routine activities, are fruitless unless they make available the elements of service to the people who need them. The availability of services is one of the basic factors in the evaluation of any agency.

Availability applies also to the comprehensiveness of services. While service systems may differ greatly in number and elaboration of component elements, and in their level of sophistication, there is a minimum constellation of such components that must be available if the needs of developmentally disabled individuals are to be met. The components described in this document are suggested as a basis for defining comprehensiveness: provisions for individual program planning and implementation, provisions for alternative living arrangements, provisions for achieving and protecting rights, and provisions for support of individual programs, including case finding, entry services, follow along, and family-related services.

The availability of these services reflects the essential human needs that are affected by disabilities. A service delivery system should have at least this degree of comprehensiveness if the needs of the population are to be met, and if the specific objectives of each agency are to be achieved. The system, moreover, should seek to have sufficient services available to provide options and alternatives, both to provide consumers with opportunities to choose from among alternative services, and to stimulate agencies providing similar services to continually seek to improve their programs.

The economics of the service delivery system, as well as the principle of normalization, dictate that all community resources, including generic services available to all citizens, should be available to disabled individuals. Agencies delivering specialized services must coordinate their programs with the resources of the general community, in order that the needs of their clients may be served in a manner that is consistent with normal community experience. The principle that no special service is provided to meet needs already appropriately served by generic agencies should be followed rigorously. Specialized services should be developed only when generic agencies are unable to accommodate special needs.

Another dimension of availability is the completeness with which the service delivery system can adequately meet the needs of all individuals. The system must make the needed services available to individuals of all ages, of all degrees and patterns of disability, of all socioeconomic and ethnic subcultures, and of both sexes; and it must make services available in the forms appropriate to these differences. This does not mean that every agency should provide direct services to everyone, but every agency must be an integral part of a system that does.

Finally, availability involves an element of balance in the modalities of service provided to disabled individuals and to the community as a whole. While the central focus must be on the well-being of people, balance may require various forms of intervention to protect the individual's interest, promote the individual's human resources, or prevent further damage to the individual's integrity. The agencies in the service delivery system should contribute directly to humanity's well-being through community information and education programs, community-wide prevention programs, and the advancement of knowledge through research. Balance of these elements within the system should be reflected in the particular balances determined to be appropriate to its individual agencies.

Accessibility

Services available in the community cannot be rendered if they are not accessible to the individuals who need them. Access may be limited by such factors as lack of information, bureaucratic red tape, immobility, household responsibilities, fear, geographic or social isolation, lack of transportation, language or other cultural barriers, cost, or the agency's lack of responsiveness and follow through.

Each service delivery system should have an affirmative action policy to facilitate access by all who need it. This policy should be reflected in operating procedures that minimize the effect of all potential barriers to access. The policy should call for:

- an active, aggressive community information program that utilizes all communication media, civic groups, and social agencies to inform people of the availability of services, and to foster public education in the needs and objectives of such services;
- a fixed point of access in the community to which all appeals may come, and through which appropriate referrals to specific agencies may be made;

- a service responsible for maintaining contact with the developmentally disabled individual over his or her lifetime, to provide necessary continuities or resumptions of service;
- operating practices that assure service within reasonable travel time, distance, and cost, regardless of family income or length of residency in the community; and
- affirmative action that energetically seeks to break through existing discriminatory barriers in the community, whether overt or covert, in order to maintain equal access to service. This should be enhanced by corresponding affirmative action to maintain equal opportunity in agency staffing.

Individualization

The focal point of the service delivery system must be the individual in need. Too often in the past, society's response to atypical individuals has been to program by category. Once the individual was identified with a particular deviant group, certain program packages were presumed applicable, such as assignment to a special class, institution, or government agency. Such an assignment was often accompanied by denial of other concurrent program options. For example, a crippled children's program may not have accepted a retarded child for remediation of physical disability, the cerebral palsied child may have been denied speech therapy, and both may have been excluded from foster care under the child welfare program. Thus, labels led to the application of standardized remedies, rather than to individual program planning with effective program coordination.

It is now increasingly recognized that disabled individuals, like other citizens, should have access to a variety of options in order to secure the most effective and acceptable means of reducing disabilities. Such access requires the conditions of availability and accessibility described in the preceding sections. It also requires the development of mechanisms for selecting and assessing the particular resources most suited to meet each individual's needs.

This concept is consistent with the principle of normalization, inasmuch as it is normal for citizens to exercise initiative and choice in accepting or rejecting various components of the health, education, and social service systems. However, individuals, or the families of individuals, with extraordinary needs for specialized services require special assistance in analyzing their own needs and in selecting appropriate programs of available resources. Special assistance is necessary for the following reasons: the nature, character, and location of needed services may be less apparent to the disabled individual than to the ordinary citizen; the disabled individual may have a diminished ability to seek out and choose both generic and special resources; and the needs of a disabled individual are likely to require multiple services over an extended period of time, requiring an exceptional sophistication in composing and implementing the individual program plan in a consistent manner. The individual program planning process becomes, therefore, a critical factor in providing services to developmentally disabled individuals.

Implied in the concept of individualization of services are a number of principles that should permeate all service delivery systems. One such principle is acceptability. The way in which services are organized and delivered must be congruous with the social and cultural values of the recipients, as well as of the providers of service. For example, the names of agencies, the labels applied to their clients, and the way these clients are interpreted to the public must be appropriate to their purposes and programs, must support the dignity of the individuals served, and must safeguard their personal and legal rights.

One means of assuring individualization of services is to allow individuals and their personal or legal representatives to participate in the decision-making processes affecting them. Although this participation should occur in all phases of individual program planning, it is especially critical at those major transitional stages in the individual's life when new service programs are required.

Regardless of the effectiveness of agency services, many developmentally disabled individuals who receive services will continue to spend a major portion of their time in their parental homes. Ordinarily, the parent or parent surrogate is the primary advocate for the young disabled individual. It is essential, therefore, that the parents' role as the prime programmers be recognized. Parents need help early in understanding and accepting the diagnosis, in knowing the reasons for the prescribed services, and in recognizing their role in implementing designed programs.

Parents should be asked to assist not only in devising the individual program plan, but also in assuming an appropriate role in executing the plan. Without parental participation, the gains from training programs and early care may be dissipated or negated when the individual is at home. When educational and employment programs are implemented, parental support and understanding is critical in promoting the maximum independence of the individual. Increasingly effective parent participation will come with increasing knowledge and acceptance. The agency, therefore, should provide counseling, supportive services, and repeated demonstrations in order to gain the benefits of full parent participation.

Documentation

Adequate record keeping and effective communication are indispensable to the continuity of individual program planning. Because this is an especially sensitive aspect of service delivery, it must be handled with great care. Although records must be adequate to assure continuing understanding and effective assistance by the staff, they should not reduce the individual to a series of abstract entries in a filing system. While records must furnish documentary evidence of the individual's progress and of his or her response to services, the dangers of rigid interpretation, over-prediction, and self-fulfilling prophecies must be avoided. Records must provide a reliable source of information and a means of communication among all persons and agencies contributing to the individual's program. Consequently, the service delivery system should assure that records move between agencies with ease and dispatch. However, the rights of the individual to privacy and confidentiality of information must always be safeguarded. In extracting data from records for research and education, the anonymity of the individual must always be preserved.

Quality Control

The purpose of standards is to promote services of high quality. Quality is not something that just happens to an agency's program; it is something that must be promoted, developed, protected, and controlled. To assure services of high quality, the agency and its service delivery system must have built-in mechanisms for monitoring the quality of services, and for making necessary reforms promptly and efficiently.

While compliance with valid standards is important for assuring services of high quality, the quality of an agency's services cannot be measured solely by their conformance to standards. Quality can be measured only by comparing the results of efforts with goals and objectives. Each agency must demonstrate, therefore, that it has effective methods for comparing outcomes with goals, and that ongoing program evaluation is coordinated with a built-in mechanism for the consequent review and modification of agency operations. The effectiveness of the services provided by an agency that has responsibility for planning or implementing individual program plans must be measured in terms of the progress of the individuals served toward the objectives that are specified in their individual program plans.

Accountability

The accreditation process is one means by which an agency may demonstrate accountability. By conducting a self-survey to assess its operations against the nationally recognized standards contained in this document, and then by participating voluntarily in an evaluation conducted by the accrediting body, the agency can demonstrate accountability to the persons who support it and to the individuals it serves. Ideally, the agency will share the results of the accreditation survey with the public, and will use the survey recommendations to improve its programs and to achieve or maintain accredited status. Because neither accreditation nor accountability can be maintained by a one-time effort, the agency must also continually monitor its operations against the standards, and strive to raise its level of compliance with each successive survey.

In demonstrating accountability, agencies should comply with the principles of the service delivery system, as these principles are expressed in the standards in this document. These principles are philosophically defensible and desirable in practice, and they will, if fully implemented, accommodate the needs of every developmentally disabled individual.

7.1 Coordination

Definition

Coordination is the process of arranging necessary resources in the appropriate sequence to accomplish a given objective. Coordination involves initiating, sustaining, and interrelating the various parts of the service delivery system.

Principles

Because developmentally disabled individuals manifest a variety of symptoms that may be related to diverse social, educational, and health factors, a single agency or discipline cannot be expected to serve the total needs of an individual and an individual's family, nor should any agency or discipline claim primacy in providing needed services. Effective access to services requires each agency in the service delivery system to serve as a resource to the individual and the family, and to provide linkage to all other necessary services within the system. A high degree of communication, cooperation, and coordination is therefore required among all the components of the service delivery system. In order to assure continued improvement in the quality of services rendered, the service delivery system should require each component agency to meet minimum standards of excellence, and to accept responsibility for review and regulation of the system.

Standards pertaining to all agencies

____7.1.1* The agency has a directory of all other resources and services within the service delivery system.

____7.1.2 The agency has written, cooperative agreements with other components of the service delivery system.

____7.1.3* The agency has established and written procedures for coordination with other components of the service delivery system. These include, but are not necessarily limited to, procedures for:

____7.1.3.1 coordinated planning of services with other agencies,

____7.1.3.2 referrals of individuals to other agencies, and

____7.1.3.3 follow-up referrals.

____7.1.4* The agency works with other agencies in the service delivery system to develop a continuum of services to meet all the needs of developmentally disabled individuals.

____7.1.4.1 The number of individuals served by agencies in the service delivery system is consistent with the needs for service, as determined by a survey of community needs.

____7.1.4.2 The agency has evidence of its involvement with the community public housing planning process to assure accommodation to the needs of developmentally disabled individuals with various levels of disability.

7.1.5 As a part of the process of coordinating services within the service delivery system, the agency:

____7.1.5.1 compiles data concerning individuals denied or excluded from services because of their unique mobility needs; and

____7.1.5.2* documents its active engagement in eliminating architectural barriers or in modifying equipment and facilities to overcome such barriers.

____7.1.6* The agency participates in a regular, at least annual, review of the service delivery system that is documented, with findings and consequent modification and action plans recorded. The review includes, but is not necessarily limited to:

____7.1.6.1 the design of system and agency approaches to solving problems;

____7.1.6.2 joint efforts between agencies to resolve problems in providing services;

____7.1.6.3 the need to integrate ongoing programs within the system;

____7.1.6.4 the identification and resolution of conflicting policies and practices;

____7.1.6.5 the identification and resolution of unnecessary duplication or uneven distribution of services;

____7.1.6.6 the need to simplify and combine administrative, operational, and funding procedures;

____7.1.6.7 the coordination of data collection and the use of data in studying the characteristics and needs of the community; and

____7.1.6.8 the development of standards for personnel selection and performance, and for program evaluation.

7.2 Resource Information and Data Documentation Services

Definitions

A resource information service compiles and disseminates up-to-date and complete listings of all appropriate resources, referral procedures, and other pertinent information. A data documentation service collects and disseminates data that are useful for planning and coordinating activities.

Principles

A single agency within each service delivery system should provide centralized resource information and data documentation services to other agencies in the system. This agency should concentrate on serving other agencies and professional practitioners. When it is not possible for a single agency to provide these services, each agency in the system should be equipped to provide at least resource information services, including information concerning referral procedures and the availability and quality of services. The agency that assists the individual to enter the system should provide more detailed referral service.

The data documentation service should provide a centralized retrieval system that promotes a standardized reporting system, following state and national patterns, so as to simplify data collection and eliminate duplication of requests to local agencies. The collected data should be useful for planning and coordinating purposes, and should help to identify the full range of services that are needed but not provided in the community.

Standards pertaining only to agencies providing resource information service

____7.2.1* The resource information service is a clearly identified point of contact for professionals and agencies seeking assistance. The service:

  ____7.2.1.1 maintains a current directory of local resources;

  ____7.2.1.2 has directories of regional and state agencies serving the local area;

  ____7.2.1.3 has procedures for obtaining, cataloging, and updating information concerning resources;

  ____7.2.1.4 has written policies that describe minimum standards for services to which referrals are made;

  ____7.2.1.5 regularly follows up on its referrals to determine if they were completed, and if they were appropriate to the request for assistance;

____7.2.1.6 analyzes referral requests quarterly to determine changing needs and programs, and to provide feedback for planning and coordinating purposes;

____7.2.1.7 actively disseminates information about its activities, so as to facilitate the resource information and referral activities of other agencies;

____7.2.1.8 works with other agencies to improve resource information and referral services; and

____7.2.1.9 makes materials available for inservice training and community education.

Standards pertaining only to agencies providing data documentation service

____7.2.2* The data documentation service coordinates its activities with those of other data collection agencies, in order to minimize duplication of effort and to encourage the use of standardized reporting systems. The service:

____7.2.2.1 collects data at least annually from all agencies in the service delivery system;

____7.2.2.2 provides consultation to local agencies in the design of agency reporting systems;

____7.2.2.3* disseminates data for use in community education and social action programs; and

____7.2.2.4* regularly categorizes the reasons why individuals are rejected for service, and reports this information to planning and coordinating bodies as a means of stimulating program modification and development.

Standards pertaining to all agencies

____7.2.3 If a resource information service is not available, the agency has a written plan outlining how it is working with other agencies to make such a service available.

____7.2.4 If a data documentation service is not available, the agency has a written plan outlining how it is working with other agencies to make such a service available.

7.3 Community Education and Involvement

Definition

Community education and involvement constitutes an active program of ready, open, and honest communication with the public. The aim of the program is to create community awareness of the needs of developmentally disabled individuals, and to stimulate social action to meet those needs.

Principles

Because the programs and services described in these *Standards* are to be conducted within the mainstream of community life, it is essential that each agency effectively convey its philosophy and goals to the public. To promote full integration of developmentally disabled individuals within the general population, the agency should encourage community acceptance of them, and a corresponding broadening of the societal definition of normality. Acceptance of developmentally disabled persons as individuals and as citizens will facilitate attainment of their human and legal rights and achievement of the resources that are necessary to meet their developmental needs.

Standards pertaining to all agencies

____7.3.1 The agency establishes a locus of responsibility for public information and education activities.

____7.3.2 The agency conducts an ongoing community education program in cooperation with other agencies. The program is designed to:

    ____7.3.2.1* create community awareness and acceptance of developmentally disabled individuals, and facilitate their integration into the community;

    ____7.3.2.2* provide information to the community concerning causes of developmental disabilities, as well as methods of prevention; and

    ____7.3.2.3* educate the general public concerning services for developmentally disabled individuals that are available, and needs that remain unmet.

    ____7.3.2.4* Specific attention is focused on understanding the general and special needs of developmentally disabled individuals, and on the right of disabled citizens to participate in the mainstream of community life.

7.3.3 The agency's community education program employs a variety of techniques, such as:

    ____7.3.3.1* brochures on services currently provided;

    ____7.3.3.2 fact sheets describing program components;

    ____7.3.3.3 newsletters;

    ____7.3.3.4 audiovisual materials;

____7.3.3.5 a speakers bureau;

____7.3.3.6 program presentations, meetings, and seminars;

____7.3.3.7 school and college class presentations;

____7.3.3.8 a total media publicity program, including press releases, staff interviews, and consumer interviews; and

____7.3.3.9 a library and bibliography of books and publications for staff and the general public.

____7.3.3.10 The agency develops and distributes public information materials in the predominant languages of the residents of the community that it serves.

____7.3.4 The agency identifies, and conducts informational sessions for, special audiences, such as public officials and staffs of generic agencies.

____7.3.5 The agency conducts educational sessions for public and private officials on the advantages of normalized services for developmentally disabled individuals.

7.3.6 The agency has a written plan outlining how it is working with other agencies and organizations to:

____7.3.6.1 eliminate restrictive zoning regulations, and

____7.3.6.2 promote laws and licensing requirements that facilitate establishing and funding normalized alternative living arrangements and other services.

____7.3.7 The agency participates with other agencies in educating law enforcement agencies, the courts, and the local bar association concerning developmental disabilities and the special needs of developmentally disabled individuals.

____7.3.7.1 The agency informs law enforcement officials, the courts, and the local bar association of the resources it has available in the event that a developmentally disabled individual comes into conflict with the law.

____7.3.7.2 The agency works with law enforcement officials and the courts in establishing a system that provides recognition of diminished responsibility, when appropriate, and a means for avoiding unnecessary or undue confinement of developmentally disabled offenders.

7.3.8 Community involvement is obtained by methods that include, but are not necessarily limited to:

____7.3.8.1 using volunteers in the community education program;

____7.3.8.2 involving citizens in writing and contacting their legislators in support of needed legislation;

____7.3.8.3 sponsoring special events that appeal to broad community interests, in order to obtain support for program needs;

____7.3.8.4 conducting activities that express and recognize citizen support of program needs;

____7.3.8.5 recognizing community leaders for their participation in and support of new program developments;

____7.3.8.6 encouraging fraternal, civic, and social organizations to support programs for developmentally disabled individuals; and

____7.3.8.7 **encouraging fraternal, civic, and social organizations to invite developmentally disabled individuals to become members and to participate in activities.**

____7.3.9 **The agency has procedures for disseminating information relating to an unusual incident involving an individual or individuals served.**

7.4 Prevention

Definitions

Primary prevention refers to preventing the occurrence of developmental disabilities by mitigating or eliminating factors in life of which developmental disabilities may be a consequence. Secondary prevention refers to preventing symptoms of developmental disabilities from occurring by early case finding and intervention. Tertiary prevention refers to ameliorating the effects of a developmental disability, and to reducing the impairment associated with it, by providing appropriate services to developmentally disabled individuals and their families.

Principles

Because of the multiple etiologies of developmental disabilities, preventive services must cover a broad range, including both socio-enviornmental and biomedical preventive activities. Preventive services should be available to each community. While agencies providing services to developmentally disabled individuals may not provide generic primary preventive services, each agency should be aware of such preventive programs, and information concerning prevention should be included in all community education and information programs. Since service agency staff members should be especially aware of the need for prevention, one of their responsibilities should be to provide and disseminate information concerning needed and available preventive programs. The application of currently available preventive techniques could reduce the future need for direct services to developmentally disabled individuals.

Standards pertaining to all agencies

____7.4.1* The agency maintains current information concerning preventive services available in the community.

7.4.2 The agency participates with other agencies in promoting the implementation of such community-wide preventive activities as:

____7.4.2.1 providing information concerning prevention in community education and information programs;

____7.4.2.2 socio-environmental preventive activities, such as preventing poisoning from lead and other toxic agents, accidents, child abuse, and fetal alcohol and other drug syndromes; and

____7.4.2.3 biomedical preventive activities, such as providing maternal health services, including family planning and conceptual and interconceptual care; natal and neonatal care; child health services, including immunization; and screening and counseling for genetic disorders.

7.5 Manpower Development

Definition

Manpower development is the cooperative process through which agencies strive to assure the availability of an adequate present and future supply of qualified personnel to provide services to developmentally disabled individuals.

Principles

Each agency has a responsibility to become involved in manpower development and training for all job levels—nonprofessional, paraprofessional, and professional. Affiliations and close working relationships should be established with local and nearby manpower training programs. Agency resources, including programs, facilities, and staff time, should be made available for visitations, field placements, internships, and related training activities. The planning and design of all manpower training should be based on periodic assessments of future staff needs and current staff competencies.

Standards pertaining to all agencies

____7.5.1 The agency specifies its role in manpower development.

____7.5.2* The agency cooperates with other agencies to assure the availability of an adequate present and future supply of qualified personnel.

____7.5.3* The agency establishes working relationships with nearby colleges and universities. The agency:

    ____7.5.3.1 makes its resources available for training and research, while maintaining its primary goal of serving developmentally disabled individuals and their families;

    ____7.5.3.2 permits exchange of staff between itself and colleges or universities for teaching, research, and consultation;

    ____7.5.3.3 allows students to visit and observe its programs;

    ____7.5.3.4 allows students to participate in field placements that are supervised by agency staff; and

    ____7.5.3.5 assists colleges and universities, as requested, in developing appropriate curricula.

____7.5.4* The agency establishes working relationships with other manpower training programs. Such relationships include provisions for:

    ____7.5.4.1 follow-up and feedback regarding the effectiveness of training programs, ____7.5.4.2 identification of new manpower training needs, and

____7.5.4.3 annual evaluation of manpower training programs.

____7.5.5 The agency seeks to initiate, and participate in, training programs conducted by University Affiliated Facilities, where available.

Appendix A

Indices to Standards

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B. Index of standards requiring actions prior to, at, or following specific times of occurrences 144
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*Table A. Index of standards pertaining to agencies applying for survey**

SECTION	STANDARDS PERTAINING TO ALL AGENCIES	STANDARDS PERTAINING ONLY TO AGENCIES PROVIDING THE SERVICE	STANDARDS PERTAINING ONLY TO AGENCIES NOT PROVIDING THE SERVICE
1. Individual Program Planning and Implementation			
1.1 The Interdisciplinary Process	all		
1.2 Evaluation and Assessment	all		
1.3 The Individual Program Plan	all		
1.4 Individual Program Implementation	all		
1.4.1 Physical Development and Health	all		
1.4.2 Mobility	all		
1.4.3 Habilitation, Education, and Training	all		
1.4.4 Work and Employment		Agencies providing *or obtaining:* all standards	
1.4.5 Recreation and Leisure	1.4.5.1 through 1.4.5.3	leisure: 1.4.5.4 through 1.4.5.4.4; recreation: 1.4.5.5 through 1.4.5.7.7; therapeutic recreation: 1.4.5.8 through 1.4.5.8.3	
1.4.6 Behavior Management	all		
1.5 Individual Program Coordination	all		
1.6 Programming Records	all		
2. Alternative Living Arrangements			
2.1 Attention to Normalization and Use of Least Restrictive Alternatives	2.1.1 through 2.1.3.12	2.1.4 through 2.1.20	
2.2 Homemaker and Sitter/Companion Services		homemaker: 2.2.1.1 through 2.2.1.7; sitter/companion: 2.2.2.1 through 2.2.2.2	
2.3 Temporary-Assistance Living Arrangements		all	
2.4 Surrogate Family Services		all	
2.5 Congregate Living Services			
2.5.1 The Congregate Living Environment		all	
2.5.2 Staffing and Staff Responsibilities		all	
3. Achieving and Protecting Rights			
3.1 Attention to Individual Rights and Responsibilities	all		
3.2 Advocacy			
3.2.1 Self Representation	all		
3.2.2 Personal Advocacy		3.2.2.1 through 3.2.2.6.6	3.2.2.7 through 3.2.2.8
3.2.3 Agency Advocacy	all		

SECTION	STANDARDS PERTAINING TO ALL AGENCIES	STANDARDS PERTAINING ONLY TO AGENCIES PROVIDING THE SERVICE	STANDARDS PERTAINING ONLY TO AGENCIES NOT PROVIDING THE SERVICE
3.3 Protective Services	3.3.1 through 3.3.3	protective: 3.3.6 through 3.3.12; guardianship: 3.3.13 through 3.3.20	3.3.4 through 3.3.5
4. Individual Program Support			
4.1 Agency Philosophy, Policies, and Procedures	all		
4.2 Case Finding	all		
4.3 Entry, Admission, and Discharge	all		
4.4 Follow Along	4.4.1 through 4.4.3	4.4.4 through 4.4.10	
4.5 Family Related Services			
4.5.1 Home Training Services		4.5.1.1 through 4.5.1.1.12	4.5.1.2
4.5.2 Family Education Services	all		
4.6 Professional Services	all		
4.7 Staffing and Staff Qualifications	all		
4.8 Staff Training	all		
4.9 Volunteer Services	all		
4.10 Governance and Management			
4.10.1 Governing Body and Administration	all		
4.10.2 Fiscal Affairs	all		
4.10.3 Personnel Policies	all		
4.10.4 Documentation	all		
4.11 Program Evaluation	all		
4.12 Provision and Maintenance of Facilities and Equipment	all		
5. Safety and Sanitation	all		
6. Research and Research Utilization	6.1 through 6.2	6.3 through 6.9.3	
7. The Agency in the Service Delivery System			
7.1 Coordination	all		
7.2 Resource Information and Data Documentation	7.2.3 through 7.2.4	resource information: 7.2.1 through 7.2.1.9	data documentation: 7.2.2 through 7.2.2.4
7.3 Community Education and Involvement	all		
7.4 Prevention	all		
7.5 Manpower Development	all		

*As noted in the Introduction, among the standards that pertain to an agency, one or more standards may be inapplicable to the agency's particular operation. In general, applicability is determined with reference to the needs of individuals served by the agency: a standard may be inapplicable to an agency if the service or activity it requires is not necessary to meet the needs of the individuals served. In addition, compliance with certain standards may be achieved if the activities they require are provided by other agencies within the agency's service delivery system.

*Table B. Index of standards requiring actions prior to, at, or following times of occurrences**

OCCURRENCE	TIME	ACTION	STANDARD
Entry	Within 3 months following	Recording of review and updating of information	1.6.3.1
		Recording of individual program plan	1.6.3.2
Enrollment or admission	Prior to enrollment or admission	Comprehensive evaluation of individual	4.3.7
		Preplacement visit by individual and family	4.3.6
		Pre-admission counseling of individual and family	4.3.9.3
		Recording of information concerning individual and family	4.10.4.2
	On admission	Placement of individual in program group	4.3.10
		Taking of medication history	4.6.15.1
	On enrollment	Assignment of individual program coordinator	1.5.1
	Within one month following enrollment	Review and updating of evaluations prior to enrollment	1.2.11.1
		Recording review and updating of information	1.6.3.1
		Completion of assessment to develop initial individual program plan	1.2.11
		Reviewing and updating individual program plan developed prior to enrollment	1.3.1.2
		Development of initial individual program plan	1.3.1.1
		Recording of individual program plan	1.6.3.2
Individual program plan employing restraint	Prior to implementation	Review by behavior management committee	1.4.6.9.1.2.1
		Review by human rights committee	1.4.6.9.1.2.2
Individual program plan employing drugs for behavior management	Prior to implementation	Review by behavior management committee	1.4.6.10.1.4.1
		Review by human rights committee	1.4.6.10.1.4.2
Individual program plan employing aversive conditioning or time-out devices	Prior to implementation	Review by behavior management committee	1.4.6.11.1.1
		Review by human rights committee	1.4.6.11.1.2
Transfer of individual	Prior to implementation	Visit by individual to site of transfer	4.3.12.2
Modification of rights	Prior to implementation	Advising individual and family of process	3.1.4.1

*Note that all standards are not applicable to all agencies. For applicability, specific requirements, and possible exceptions, refer to standards listed.

Table B continued

OCCURRENCE	TIME	ACTION	STANDARD
Provision of homemaker services	Prior to implementation	Evaluation of family's needs	2.2.1.5
		Informing homemaker of family's situation	2.2.1.6
Surrogate family placement	Prior to implementation	Orientation and training of surrogate families	2.4.2
Research	Prior to implementation	Review by research committee	6.6.2.1
Individual's attainment of majority or emancipation	At review of individual program plan by interdisciplinary team	Documentation of:	
		consideration of individual's exercise of rights	3.1.6.1
		consideration of individual's need to remain in residential program	3.1.6.2
		determination of individual's need for guardianship	3.3.2.2
		Continuation or reestablishment of guardianship	3.3.20
Alleged instance of abuse or neglect	Immediately	Report of instance to chief executive officer	3.1.8.6.1
	Within 24 hours	Report of instance to chairman of human rights committee	3.1.8.6.2
		Report of investigation to chief executive officer	3.1.8.7.2
Termination of agency services	Within 7 days	Discharge summary entered in individual's record	4.3.13.4
Performance of autopsy	Within 72 hours	Provisional anatomic diagnoses recorded	4.3.14.2
	Within 3 months	Complete protocol entered in record	4.3.14.2

*Table C. Index of standards requiring actions at specific intervals**

INTERVAL	ACTIONS PERTAINING TO INDIVIDUALS	STANDARD	OTHER AGENCY ACTIONS	STANDARD
Every 30 minutes	Check individual in restraint and record checks	1.4.6.9.2.2		
Every 2 hours	Record provision of opportunity for motion and exercise for individual in restraint	1.4.6.9.2.4		
Daily	Implement activity schedule	2.5.2.5	Meet clothing needs	4.12.8.1
			Dispose of waste	5.5.3.1.2
	Shower or bathe	2.1.17	Post menu	4.6.7.2.2
	Brush teeth	2.1.19		
At least monthly	Review of individual program plan by member(s) of interdisciplinary team	1.3.7	Review drugs in living units	5.6.6
	Record individual's response to plan	1.3.7.1		
At least quarterly	Record weight	1.4.1.10	Monitor surrogate family homes	2.4.1.2
	Record height	1.4.1.10.1	Evaluate performance of personal advocates	3.2.2.4.8
			Conduct evacuation drills for each shift	5.3.3
			Analyze referral requests	7.2.1.6
At least semiannually			Evaluate personal advocacy services program	3.2.2.4.10
At least annually	Assessment as determined by interdisciplinary team	1.2.12.3	Evaluate surrogate homes	2.4.1.3
	Health assessment	1.2.12.4	Update availability of alternative living arrangements	3.3.8.1
	Audiometric screening of children under age of ten	1.2.12.5.1	Review statement of philosophy, objectives, and goals	4.1.2.7
	Speech and language screening of children under age of ten	1.2.12.5.2	Review objectives of professional services	4.1.2.9.7
	Review of individual program plan by interdisciplinary team	1.3.8	Review entry log data	4.3.15.1
			Review policies and procedures manual	4.10.1.12.7
	Record follow-along status	4.4.9	Audit fiscal activities	4.10.2.5.2

*Note that all standards are not applicable to all agencies. For applicability, specific requirements, and possible exceptions, refer to standards listed.

Table C continued

INTERVAL	ACTIONS PERTAINING TO INDIVIDUALS	STANDARD	OTHER AGENCY ACTIONS	STANDARD
At least annually	Review limitation of rights	3.1.4.6	Prepare fiscal report	4.10.2.5.3
	Provide financial accounting to individual or family	3.1.9.3	Evaluate employees	4.10.3.7
			Review job descriptions	4.10.3.9.3
	Secure reports from guardians or agencies responsible for financial interests of individuals	3.3.7.1	Review information concerning separations	4.10.3.12.3
			Review content of individual records	4.10.4.6
			Evaluate agency's performance	4.11.1
	Secure report from guardian	3.3.16	Evacuation of each shift	5.3.3.4
			Review methods for obtaining consent to research participation	6.7.5
			Participate in review of service delivery system	7.1.6
			Collect data from agencies in system	7.2.2.1
			Evaluate manpower training programs	7.5.4.3

*Table D. Index of standards requiring actions for, limiting actions to, specific durations**

ACTION	DURATION	STANDARD
Retention of record of menus served	At least 30 days	4.6.7.2.5
Retention of record of food purchased		4.6.7.5
Prescription of drugs used for behavior management	No more than 30 days	1.4.6.10.1.1
Provision of opportunity for motion and exercise for individual in restraint	Not less than 10 minutes in each 2 hours	1.4.6.9.2.4
Application of restraints as time-out devices	Not more than 15 minutes	1.4.6.11.6
Ordering application of restraint	No more than 12 hours	1.4.6.9.2.1
Timing out	No more than 1 hour	1.4.6.11.5.1

*Note that all standards are not applicable to all agencies. For applicability, specific requirements, and possible exceptions, refer to standards listed.

Appendix B

Accreditation Policies and Procedures

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I. Principles governing accreditation survey procedures

A. The criteria specifying adequate services for developmentally disabled individuals are stated in the standards. The purpose of an accreditation survey is to assess an agency's compliance with the standards.

B. An agency's compliance with the standards will be assessed in the following ways:
   1. statements of responsible, authorized administrators or staff members;
   2. certification or other documentation provided by the agency;
   3. the agency's responses to questions in a *Survey Questionnaire*; and
   4. on-site observations by the Council's surveyors.

C. Since all standards are important to the provision of fully adequate services, an agency that is to be surveyed must report its self-assessment of compliance with every standard applicable to its operation.

D. Before scheduling an on-site survey to be conducted by the Council's surveyors, a review of the agency's self-assessment of compliance, together with the supportive materials supplied by the agency, will enable the Council to inform the agency if it is ineligible for accreditation according to the Council's stated criteria. In the event of such ineligibility, the agency will have the option of not proceeding with an on-site survey. (However, see paragraph H below.)

E. During an on-site survey, the Council's surveyors will concentrate on:

1. observing the implementation of pertinent standards in the services being delivered to a representative sample of individuals served by the agency, through the conduct of program audits of such individuals;
2. resolving questions concerning compliance that remain after an agency has reported its self-assessment of compliance and provided supplementary information and/or documentation;
3. conducting a Public Information Interview with representatives of individuals served by the agency, other organizations to which the agency relates, and the general public; and
4. reviewing and discussing survey results with the agency's staff.

F. For most standards, it is generally impossible to determine whether an agency is in full compliance. For example, to determine full compliance with the standard requiring that every individual have an individual program plan would mandate review of every individual served by the agency. Time constraints preclude that. Consequently, surveyors use samples to ascertain whether there is failure to comply with the standard. If every individual in the sample has a plan, the surveyors report that they have found no deficiencies in meeting that standard. If one or more individuals in the sample does not have a plan, the surveyors indicate that the agency has not fully complied with the standard. (A fuller explanation of this procedure and the reasons for it is contained in the section entitled "Conduct of the On-Site Survey" in the *Survey Questionnaire for use with the Standards.)*

G. A self-survey of its compliance with applicable standards, conducted by its own staff, should be of benefit to an agency regardless of whether or not it is followed by an on-site survey conducted by the Council's surveyors. Therefore, agencies are encouraged to conduct self-surveys, whether or not they apply for accreditation survey, and the *Survey Questionnaire for use with the Standards* will be available to agencies whether or not they apply for survey.

H. Similarly, an on-site survey by the Council's surveyors, who will compare their assessments of compliance with the assessments made by the agency's own staff, should be of benefit to an agency regardless of whether or not accreditation is attained. Therefore, agencies are encouraged to apply for accreditation survey even if they are ineligible for accreditation.

II. Eligibility for survey

A. An agency is eligible for survey by the Council if it:

1. is an organization that provides services to—though not necessarily exclusively to—developmentally disabled individuals or their families;
2. provides services to individuals as part of a process of developing, implementing, and periodically reevaluating an individual program plan for each individual served;
3. is, or is seeking to become, part of a service delivery system offering services that meet the needs of all developmentally disabled individuals within the community that it serves;
4. operates without limitation by reason of race, color, or national origin;
5. operates in accordance with clearly defined administrative responsibility;
6. possesses a current license to operate, if such is required by the state in which it is located; and
7. has been in operation under the same ownership or control for at least one year, so that there is a record of performance that can be evaluated.

B. A separate, identifiable unit or component of an organization that provides other services may be eligible for survey under the above criteria. (But see the following Section: *Services included in a survey.)*

C. The agency must complete and return an Application for Survey, a *Survey Questionnaire*, a Statement of Compliance with Safety and Other Requirements for each of its buildings, and any other documents required by the Council. The agency must provide, or authorize the Council to obtain, as required, official records and reports of public or publicly-recognized licensing, examining, reviewing, or planning bodies, for review by the Council in determining the agency's compliance with standards.

D. The agency must pay the fees required for survey materials, for the Council's review of materials submitted by the agency, and for the on-site survey.

E. An agency may be eligible for survey whether or not it is eligible for accreditation. An agency that is ineligible for accreditation may nevertheless receive the educational and consultative benefits that constitute the major advantages of an accreditation survey.

III. Services included in a survey

A. Agencies offering two or more categories of service must seek accreditation for all service categories for which the Joint Commission offers accreditation. This requirement will be waived for newly established categories of service in the agency in their first year of operation.

B. Accreditation decisions for each service surveyed shall be made independently, but to retain any Joint Commission accreditation, an agency must apply annually for survey of each service category that is not accredited or is accredited for one year. The determination to survey or to defer survey shall be made by the pertinent accreditation program(s).

C. If any service category is surveyed under the above provisions four consecutive times and fails to be accredited for a period of two years, accreditation of all other service categories shall, except in rare and unusual circumstances involving extreme hardship, be denied or revoked, whether or not any other service category is surveyed at the time of the fourth failure of the subject category.

D. A hospital unit within an agency providing residential services must be surveyed as a hospital by the Hospital Accreditation Program of the Joint Commission. An infirmary unit within such an agency does not require a separate survey.

E. The following criteria distinguish an infirmary from a hospital:

1. An infirmary is not listed as a hospital or hospital unit in the American Hospital Association's *Guide to the Health Care Field*, and
2. An infirmary does not provide facilities for:
    a) elective surgery or emergency surgery requiring general or regional anesthesia;
    b) the care of life-threatening illness; or
    c) intensive care.
3. An infirmary does provide:
    a) facilities and equipment for first aid and repair of simple lacerations that can be performed under local anesthesia;
    b) temporary care until transfer to an accredited hospital can be arranged;
    c) intermediate care, day and night, for observation or noncritical medical illness; and
    d) general medical care, the nature of which would require only simple and infrequent routine screening laboratory examinations. Treatment may include parenteral fluids and various drugs administered over a short term.
4. An infirmary may provide diagnostic x-ray, laboratory, and pharmacy services.

*IV. Steps in the survey and accreditation process**

A. The administration and staff of the agency familiarize themselves with the standards, survey eligibility requirements, and survey and accreditation policies and procedures. (Such familiarity may be facilitated by a two-day accreditation workshop, as described on page xiv of the "Introduction." An on-site workshop, described on page 161, is intended for an agency that is actively implementing the standards. It is specifically designed to assess whether the agency's staff possesses an accurate understanding of the standards, as demonstrated by its efforts to implement them.)

B. The agency submits an Application for Survey that provides the information necessary for determining:

  1. the agency's eligibility for survey,
  2. other accreditation programs of the Joint Commission that are applicable to the agency and to which it must apply (see the previous Section: *Services included in a survey),*
  3. the number of individuals on whom program audits will be conducted during the on-site survey, and
  4. the number of surveyor-days that will be required for an on-site survey, and the cost of the survey.

C. When an accredited agency is required to apply for resurvey, its completed Application for Survey must be received within 20 days of the agency's receipt of notification that application for resurvey must be made.

D. Except when a publicly-operated facility is prohibited from doing so by law, the agency must submit, along with its Application for Survey, a nonrefundable deposit in the amount required by the Council. A portion of the deposit will be applied to the charge for the on-site survey of the agency by the Council's surveyors, if such an on-site survey is subsequently conducted, or to the charge for review of the agency's *Survey Questionnaire* by the Council, if an on-site survey is not conducted. The remainder of the nonrefundable deposit will be applied to the cost of the *Survey Questionnaire* and other survey materials that are supplied to the agency.

E. If the agency is found to be eligible for survey, it is advised of the cost of an on-site survey and provided with the *Survey Questionnaire* and other materials required for reporting the results of its self-survey to the Council. These materials require the agency to:

  1. report whether it is in full compliance, partial compliance, or noncompliance with each standard, or if a standard is not applicable to it, or if the activity required by the standard is provided by another agency within the agency's service delivery system;
  2. explain each reported instance of partial compliance or nonapplicability, and each instance in which a required activity is provided by another agency;
  3. submit documentary evidence or certification of compliance with certain standards; and
  4. answer questions concerning, or give examples of, the implementation of certain standards.

F. The agency submits its completed *Survey Questionnaire*, as well as other materials required by the Council. These materials must be submitted within two months after receipt by the agency. In unusual circumstances, this interval may be extended to no more than four months. An Application for Survey will expire if this requirement is not met. When this occurs, a new application, accompanied by a nonrefundable deposit, must be submitted if a survey is desired.

G. The completed *Survey Questionnaire* and other materials are reviewed by the Council to determine the compliance with the standards that is reported therein. If this review reveals that the agency is ineligible for accreditation, according to the Council's stated criteria, the agency is so advised, and it may elect not to proceed with an on-site survey.

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*The sequence of events in the accreditation survey process is summarized in Table I on page xvii of the "Introduction."

However, since a survey is believed to be of benefit whether or not accreditation is attained, the Council encourages an on-site survey in every case.

H. The agency is notified of the date of the survey and the surveyors who will conduct it. While final authority for scheduling the survey rests with the Council, every effort is made to arrange the survey in such a manner as to be most convenient to the agency. The survey will ordinarily be conducted within two months following the Council's receipt of the agency's completed *Survey Questionnaire*. Delays requested by the agency may be granted to a maximum of six months following the Council's receipt of the agency's completed *Survey Questionnaire*. Otherwise, the agency's Application for Survey expires. When this occurs, a new application, accompanied by a nonrefundable deposit, must be submitted if a survey is desired.

I. Prior to conducting the survey, the surveyor(s) will review the *Survey Questionnaire* and other materials submitted by the agency and note items requiring verification or clarification. During the survey, the surveyor(s) will conduct a Public Information Interview, conduct program audits on a sample of individuals served by the agency, assess compliance with other standards identified as requiring verification or clarification, and review their findings with the agency's staff during a Summation Conference.

J. Following the survey, a surveyor will prepare a Survey Report that identifies all standards with which the agency was found to be in less than full compliance by the surveyor(s), and that contains recommendations for correcting identified deficiencies.

K. The Council will review the Survey Report, together with any other relevant information, and make a decision regarding accreditation, in accordance with stated criteria. Following ratification of the Council's accreditation decision by the Joint Commission's Board of Commissioners, the agency will be notified of the decision and provided with a copy of the Survey Report. The reason for nonaccreditation will be specified in each instance of such a decision, and appeal procedures will provide full exercise of the agency's right to a fair hearing. (See Section XI: *Accreditation decision and appeal.)*

V. Standards that must be implemented prior to initial survey

A. Surveys conducted by the Council focus on assessing compliance with standards concerning the delivery of services in accordance with individual program plans that are reviewed at stated intervals and modified as necessary on the basis of progress toward the objectives established for each individual served. Compliance with such standards cannot be assessed adequately unless the agency has been seeking, over a period of time, to provide programming in conformance with the standards, so that its performance in providing such programming can be examined. The eligibility for survey requirement that states that an agency must have been in operation under the same ownership or control for at least one year, stems from the necessity for a performance record that may be examined during a survey of the agency. (See Section II: *Eligibility for survey,* A.7.)

B. The Council recognizes, however, that once a decision to implement the standards has been made, such implementation may have to be phased in over a period of time. Furthermore, the Council does not require retroactive implementation of standards (such as those concerning evaluation prior to admission to a residential program). In response to these considerations, the Council has established the following policy concerning the implementation of standards for which an agency will be held responsible at the time of its initial survey:

1. As stated in the Application for Survey, an agency should be thoroughly familiar with the standards applicable to it, before it files an Application for Survey.
2. An Application for Survey may be submitted at any time. An on-site survey is not usually conducted until at least three months after an application has been filed. The agency will be held responsible for implementation of all applicable standards concerning individual evaluation, program planning, and program delivery requirements during the six-month period preceding the on-site survey. The submission of the application should be timed accordingly.

3. At the time of the survey, a current and functional individual program plan must be in effect for each individual served, and all program plan review activities required during the preceding six months must have been accomplished.
4. Admissions to residential programs and enrollments in other programs must have been conducted in compliance with applicable standards for at least six months prior to the survey. The surveyor-selected sample of individuals for whom individual program audits are conducted will include some individuals admitted or enrolled within six months prior to the survey.
5. Annual activities required by the standards (for example, physical examinations, personnel evaluations, and agency program evaluations) must have been accomplished at least once prior to the survey. Initial planning of individual programs by interdisciplinary teams accomplished within the twelve months prior to the survey will be considered equivalent to the annual review of such programs required under the standards.
6. On both initial survey and resurvey, agencies are responsible for compliance with new and revised standards six months after the date on which they were finally approved. Changes in accreditation policies, procedures, and requirements are implemented six months after the date on which they were finally approved. (All changes in standards, policies, and procedures, together with their effective dates, are announced in the JCAH newsletter, *Perspectives.*)

VI. Public information interviews

A. As specified in Section IV, an agency that seeks accreditation must complete a *Survey Questionnaire* and report its self-assessment of compliance with all standards that are pertinent to its operation. The agency must also provide certification or documentation of compliance with certain standards. All of this material is reviewed by the Council's staff prior to the on-site survey conducted by the Council's surveyors. Inquiries may be made of public licensing agencies, or other relevant examining bodies, concerning the agency's compliance with standards. In addition, the Council will provide, during the on-site survey, an opportunity for presentation of information by representatives of individuals served, their families, other consumers, and the public. Anyone believing he or she has pertinent information about an agency's conformance to the standards may present this information to the surveyors.

B. Each agency to be surveyed is notified, prior to the survey, of the dates on which the survey will be conducted, and of the names of the surveyors who will conduct it. The agency is expected to share this information with anyone who requests it, and to preserve copies of letters containing such information. The agency must also post notice in a public place on its premises announcing the dates of the survey and the date and time of the Public Information Interview. The agency is required to respond to all inquiries concerning survey dates, the date and time of the Public Information Interview, and the names of surveyors, but it is not required to publish this information through any mass media. The Council will notify each Councillor and the chief executive officer of each of its Member Organizations of each survey scheduled.

C. The date and time of the Public Information Interview will be determined by mutual agreement between the agency and the surveyors when the survey is scheduled. The Public Information Interview will be attended by the administrator of the agency, or his or her chosen representative, and by other staff as agreed upon by the administrator and the surveyors. Invitations must be extended to families of individuals served—and preferably to all such families—and to parent and other consumer organizations concerned with services for developmentally disabled individuals generally, as well as with the particular services provided by the agency being surveyed. Invitations should also be extended to other organizations to which the agency relates, such as volunteer and public service groups, agencies from which services are purchased, agencies that make referrals to or receive referrals from the agency, and planning and coordinating agencies concerned with the agency's role in the service delivery system. The agency will be responsible for notifying the attendees of the exact date, time, and place of the interview. A surveyor will chair the session and receive the information. The agency will be expected to provide reasonable accommodation.

D. Public Information Interviews will not exceed two hours in duration. The interview will consist only of the orderly receipt of information offered verbally or in writing. All information received by this method will be fully considered by the Council for pertinence and verification (as is that from all other sources), and the findings will be included in the Survey Report. Further rights of participation inure to any outside source of information only when granted by the agency.

E. As stated below, all information obtained by the Council in the accreditation survey process, and the content of the Survey Report, are considered confidential between the Council and the surveyed agency. The Survey Report will be provided only to the chief executive officer and the governing body of the surveyed agency.

F. Nothing in this policy precludes the right of the Council to survey an accredited agency at any time. (See Section IX: *Requirements for and duration of accreditation.)*

VII. Survey personnel, time, and fees

A. Council surveyors who assess compliance with the standards through the program audit process must be fully qualified in one of the service professions relevant to programming for developmentally disabled individuals. They must also have had extensive and intensive experience in interdisciplinary evaluation of and programming for such individuals, including those who are multiply, severely, and profoundly handicapped. Surveyors are also required to be generalists who know the contributions that can and should be made by all disciplines to evaluation of and programming for developmentally disabled individuals. Surveyors are trained and experienced in the meaning and implementation of the standards and in methods for reliably assessing compliance with them.

B. The number of surveyors assigned to a survey and the amount of time required for its conduct will be determined by the Council.

C. Survey fees shall be based upon actual average cost, as determined annually.

D. No fees shall be required for a special survey initiated at the discretion of the Council in accordance with paragraph D of Section IX: *Requirements for and duration of accreditation.*

VIII. Survey reports

A. The Council will provide each agency surveyed with a Survey Report that identifies all standards with which the surveyors found the agency to be in less than full compliance. The Report will also contain recommendations for correcting identified deficiencies in compliance, and specify the reasons for a decision of nonaccreditation or for limiting a term of accreditation to one year.

B. Contents of the Survey Report are disseminated solely at the discretion of the agency. Except as required by law, the Council will not release any information obtained through the survey without the agency's written authorization. The Council will, however, respond to queries concerning whether or not an agency applied for survey, was surveyed and received accreditation, and concerning the duration of accreditation, if granted.

IX. Requirements for and duration of accreditation

A. An agency is ineligible for accreditation if it is found to be in less than full compliance with more than a stated percentage of the Category A standards applicable to it. Category A standards are those identified by the Council as most important for the provision of adequate services. The maximum percentage of applicable Category A standards with which accreditable agencies may be found to be in less than full compliance is determined by the Council and is the same for all agencies.

B. To be accredited, an eligible agency must meet the Requirements for Accreditation stated on page xix of the *Standards* document. If an agency, although meeting these requirements, has been found to have deficiencies in compliance with standards that, in the opinion of the Council, should be corrected within one year, accreditation is limited to a term of one year. Otherwise, accreditation is for a term of two years, or until another survey is conducted.

C. An agency may be granted one-year accreditation no more than three consecutive times.

D. An accredited agency may be resurveyed at any time at the discretion of the Council. No fees shall be charged the agency for a special survey initiated at the discretion of the Council.

E. The Council must be notified when an accredited agency changes ownership or control, or undergoes a major change in its capacity or in the kinds of services it offers. If it is the opinion of the Council that a resurvey is necessary, the agency must submit an Application for Survey within 20 days of notification by the Council. Failure to comply with these provisions will result in loss of accreditation. Examples of changes that the Council should be notified of include, but are not necessarily limited to, the following:

1. change of ownership or control, or change of licensure status;
2. change of chief executive officer;
3. increase in number of individuals served by ten percent or more of the number served at the time of the most recent survey or notification to the Council;
4. decrease in number of employees by ten percent or more of the number employed at the time of the most recent survey or notification to the Council;
5. added or discontinued categories of service covered by the *Standards*;
6. occupation of additional buildings, not occupied at the time of the most recent survey;
7. any change affecting the accuracy and currency of the Statement(s) of Compliance with Safety and Other Requirements most recently submitted to the Council; and
8. receipt of a written inspection or evaluation report that is relevant to the agency's compliance with accreditation standards requiring conformance to the sanitation, health, environmental safety, and fire safety codes and regulations of the state or local authorities having primary jurisdiction over the agency in these matters.

F. The chief executive officer of an accredited agency should notify the Council of changes, such as those described above, within 30 days of their occurrence.

G. Agencies not granted accreditation, or whose accreditation is revoked, may apply for resurvey no earlier than six months following the previous survey, or, in the event of appeal of a nonaccreditation decision, six months following a final decision of nonaccreditation.

X. *Compliance with fire safety construction standards*

A. An agency maintaining a building that does not comply with the applicable fire safety construction standards in the *Life Safety Code*, 1973 edition, of the National Fire Protection Association must:

1. replace the building, or
2. remove the individuals to a building that does comply, or
3. modify the building to comply with the standards, or
4. install an automatic fire extinguishing system in accordance with the 1973 edition of the *Life Safety Code*.

If the agency is otherwise in sufficient compliance with the standards, accreditation for two years is possible when one of the above is accomplished.

B. If a delay is involved in accomplishing one of the above, the following conditions must be met during the interim:

1. there must be a well-defined, documented plan and a reasonable schedule for the accomplishment of 1, 2, 3, or 4 in paragraph A above; and
2. there must be an excellent fire plan, frequent rehearsals and evacuation drills followed by critiques, and outstanding housekeeping, as well as the reduction of combustible material to a minimum in the interest of fire prevention.

C. One-year accreditation is the maximum that may be granted until such time as fire safety construction standards are met. A third one-year accreditation may be granted if the interim measures are being well-implemented.

D. Compliance with the "Institutional Occupancies" section of the *Life Safety Code*, 1973 edition, of the National Fire Protection Association is required only for residential buildings that contain more than fifteen beds and that house residents who are incapable of taking action for self-preservation. The "Residential Occupancies" section of the Code may be applied to other residential buildings if there are procedures that assure the orderly evacuation of any resident who is incapable of taking action for self-preservation.

XI. Accreditation decision and appeal

A. At the completion of the on-site survey, the surveyors will present their findings at a Summation Conference that is to be attended by representatives of the agency, as determined by the agency's chief executive officer. During the Conference, the surveyors will point out each instance in which their assessment of the agency's compliance with a standard differs from the agency's reported self-assessment of compliance, and the surveyors will discuss, as required, the reasons for their assessments. Representatives of the agency will be expected to seek to correct any surveyor assessments that are, in their judgment, erroneous.

B. Assessments presented by the surveyors during the Summation Conference and subsequently maintained by them will be stated in a written Survey Report. The Accreditation Council or, at its option, its Accreditation Committee, being a committee created by resolution of the Accreditation Council from its Councillors, will review the Report, together with any other relevant information received from any source, and will make a decision on accreditation. This decision will be submitted for ratification by the Accreditation Committee of the Board of Commissioners of the Joint Commission on Accreditation of Hospitals, being a committee created by resolution of the Board of Commissioners from its membership. Prior to making a decision, the Accreditation Council may request any further information, including information that may be gained from a resurvey or partial resurvey of the agency, which the Council may order to be performed.

C. The Accreditation Committee of the Board of Commissioners will either ratify the decision made by the Accreditation Council after finding that there is substantial evidence to support it, or remand the decision to the Accreditation Council. A decision to accredit the agency that is ratified by the Accreditation Committee of the Board shall constitute the final accreditation decision of the Joint Commission. A remanded decision will be reconsidered by the Accreditation Council, or, at its option, by its Accreditation Committee, and subsequently resubmitted to the Accreditation Committee of the Board of Commissioners in accordance with the provisions of paragraph B.

D. A decision to deny or revoke accreditation that is ratified by the Accreditation Committee of the Board shall entitle the agency to an interview with a representative of the Accreditation Council for the purpose of seeking to demonstrate that the agency was actually, at the time of the survey, not in less than full compliance with standards with which the surveyors reported it to be in less than full compliance and to further clarify the findings pertinent to the decision of the Accreditation Council. The agency shall be notified promptly of the ratified decision and of the right of the agency to an interview, and the agency will be provided with a copy of the Survey Report, as reviewed and approved by the Accreditation Council, indicating the deficiencies in compliance with standards that have resulted in the decision of no accreditation. If the agency's written request for such an interview is not received within 20 days following the receipt by it of such notification, the ratified decision to deny or revoke accreditation shall constitute the final accreditation decision of the Joint Commission.

E. The interview requested by the agency shall be held within 30 days following the receipt of such written request. At least 20 days prior to the interview, the agency shall be notified of its time and place. At least one of the surveyors who participated in the survey of the agency shall attend the interview. Under extraordinary circumstances, and with the mutual consent of the agency and the Accreditation Council, the number of days within which such an interview must be held following receipt of the agency's request for an interview may be increased. The presentation made by the agency at the interview and the conclusions concerning it made by the Accreditation Council's representative shall be described in a written report. The Accreditation Council, or, at its option, its Accreditation Committee, will review the report of the interview and will make a decision either to affirm the previous decision of no accreditation or to change the previous decision to accreditation, which decision will be submitted for ratification by the Accreditation Committee of the Board of Commissioners, in accordance with the provisions of paragraph B.

F. The Accreditation Committee of the Board of Commissioners will ratify or remand the decision of the Accreditation Council, in accordance with the provisions of paragraph C. A ratified decision to accredit the agency shall constitute the final accreditation decision of the Joint Commission.

G. Following an interview conducted in accordance with the provisions of paragraph D, a ratified decision to deny or revoke accreditation shall entitle the agency to a hearing before an Appeals Hearing Panel, and further, if desired, to an appeal to the Board of Commissioners. The complete formal procedures that will be followed in any hearings and appeals to which agencies are entitled will be made available at the time of any notification of a preliminary adverse accreditation decision.

H. The previous accreditation status of an agency shall be retained until a final accreditation decision is made. A final decision to accredit an agency is retroactive to the date of survey.

I. Agencies are entitled to interviews, hearings, and appeals, in accordance with prescribed procedures, in the event of denial or revocation of accreditation only, and not in respect to the duration of accreditation or the conditions under which accreditation may be awarded.

J. Whenever any decision to deny or revoke accreditation is based upon noncompliance with any standard or standards the reasonableness of which is challenged by the agency, the agency shall have the right to a hearing before the Standards Committee of the Accreditation Council on the reasonableness of any such standard or standards. Written request for such a hearing must be received from the agency within 20 days following the receipt by the agency of notification of the accreditation decision, and the hearing shall be held within 30 days after receipt of the agency's written request. Any other party who, in the judgment of the Standards Committee, may be significantly and adversely affected by any accreditation decision involving the reasonableness of any standard or standards shall be entitled, upon written request, to participate in any hearing before the Standards Committee, and any such party shall be given written notice of any such hearing and of the party's rights in connection therewith at least 20 days prior to the date of the hearing. The right of the agency and of any other person designated as an interested party, as provided above, to be accompanied by counsel, to submit written comments, to make oral presentations, and to offer testimony shall be the same as provided for hearings before the Appeals Hearing Panel.

K. The Standards Committee shall consider all materials and information offered by the agency and other interested parties participating, as provided above. After the hearing, the Standards Committee shall report to the Accreditation Council its judgment as to the reasonableness of the standard or standards challenged by the agency and may recommend any amendments for consideration and action by the Accreditation Council at its next regular meeting. Any amendment adopted by the Council shall be submitted for ratification by the Board of Commissioners. If the Board of Commissioners ratifies any amendment of any challenged standard in a manner favorable to the agency, the agency shall be entitled to a resurvey without a waiting period and without payment of an additional fee, if, in the judgment of the Accreditation Council, a resurvey is necessary to determine compliance with the amended standard.

L. A Councillor or Commissioner who is in any way affiliated with an agency shall not participate in deliberations or votes relative to the accreditation status of that agency.

XII. Accreditation certificates

A. Each agency that is granted accreditation will be provided with a certificate of accreditation indicating the year in which accreditation is granted. In the case of an agency providing services in more than one category for which Joint Commission accreditation is offered, the certificate will specify all categories of service surveyed and all categories accredited.

B. The initial certificate or new certificate, reflecting a change in name or in the categories of service accredited, will be provided without charge. The agency may secure additional certificates upon payment of the cost of reproduction.

C. The certificate of accreditation and all copies thereof shall remain the property of the Joint Commission and must be returned to the Joint Commission if the agency is issued a new certificate or if it loses its accreditation.

D. The Joint Commission will periodically publish lists of accredited agencies.

XIII. Abbreviated resurveys

A. To better serve agencies participating in the accreditation process, the Council offers two kinds of resurvey:

1. A complete resurvey is one for which an agency submits a complete *Survey Questionnaire*, together with necessary supporting materials, and which is conducted as though it were an initial survey. A complete resurvey provides a comprehensive assessment of compliance with applicable standards.
2. An abbreviated resurvey is one for which an agency submits a Progress Report in lieu of a completed *Survey Questionnaire*. The Progress Report:
   a) describes actions taken to implement the recommendations emanating from the previous survey;
   b) reports the agency's self-assessed compliance with each standard listed in the report of the previous survey, with each standard adopted or significantly revised since the previous survey, and with each newly applicable standard;
   c) explains any variance from the agency's most recent report of such compliance; and
   d) includes copies of any documents that are listed in the *Survey Questionnaire* as required to be submitted prior to survey and that have been revised since their most recent previous submission.

During the on-site abbreviated resurvey, the surveyors assess the agency's compliance with each standard with which it was previously found to be in less than full compliance; with each new, significantly revised, or newly applicable category A standard; and with each standard for which a revised self-assessment of compliance was reported. The agency must make available to the surveyors any documents that are listed in the *Survey Questionnaire* as required to be available on survey and that have been revised since the previous survey. The surveyors will initiate program audits on at least half of the number of individuals for whom audits would be conducted on initial survey; approximately half of the audits will be conducted on individuals for whom audits were conducted on the previous survey, whenever such individuals are available. Additional program audits will be conducted at the discretion of the surveyors, who will visit every living unit and activity building. The surveyors will also seek evidence that compliance with standards not listed in the previous survey report has been maintained. An abbreviated resurvey does not imply that the attention of the surveyors will be limited to certain standards: the surveyors will examine the agency's compliance with any standards that they deem appropriate to apply.

B. During the two years following its initial survey or most recent complete resurvey, and at the option of the Council, an agency may apply for an abbreviated resurvey. An agency may not receive two successive abbreviated resurveys. Each accredited agency, and each nonaccredited agency that applies for resurvey, must undergo a complete resurvey at least every four years.

C. Regardless of the kind of resurvey contemplated, accredited agencies must submit Statements of Compliance with Safety and Other Requirements as requested by the Council. Every survey includes a Public Information Interview and a Summation Conference.

XIV. Observation of surveys

A. It is the Council's intent that its procedures for assessing compliance with standards be publicly described and thoroughly understood by all concerned. The survey process is portrayed in an audio-visual presentation, which is loaned to agencies without charge, except for insurance and return postage. Further instruction in the survey and accreditation process is available through accreditation workshops offered by the Council for that specific purpose. Any individual may attend the Public Information Interview that is a part of each survey, and, with the permission of the agency's chief executive officer, may also attend the Summation Conference during which the surveyors present their findings and the reasons for them. Attendance at these activities could obviate the need for most observations of surveys.

B. Without special preparation and precautions, observation of an on-site survey may compromise the compliance assessment process. In addition, time utilized for explaining assessment practices to observers reduces the predetermined and limited time available for conducting the survey, thereby posing a threat to its effectiveness.

C. Accordingly, the presence of observers during a survey conducted by the Council must be governed by the following regulations:

   1. Staff members of the agency being surveyed may not be observers. The assessment of compliance with certain standards, as well as the need for continuing deliberations among the surveyors, requires that surveyors be free to observe and talk with agency employees and to confer with each other without the constant presence of agency administrators or supervisors.
   2. Observers may be present only as permitted and sponsored by the agency being surveyed, which assumes responsibility for protecting confidentiality concerning the individuals served.
   3. No more than three observers can be accommodated on any survey.
   4. An agency desiring to sponsor one or more survey observers must notify the Council accordingly prior to scheduling the survey.
   5. If it is necessary to spend time providing explanations and demonstrations for observers, such time will be added to the time allocated for conducting the survey and will be charged for at the regular survey fee rate.
   6. Observers may not be present when their presence would hinder surveyor deliberations, such as when pooling survey findings in preparation for presentation at the Summation Conference.

D. The above regulations do not apply to survey observation by Councillors, Council or Joint Commission staff, surveyors in training, or other persons sponsored by the Council. The agency will be notified if Councillors, Council or Joint Commission staff, or surveyors in training are to observe the survey. Other persons sponsored by the Council may observe only with the prior permission of the agency concerned. All observers sponsored by the Council will observe in accordance with guidelines established by it, and the Council will provide the necessary additional surveyor time without expense to the agency being surveyed.

XV. On-site accreditation workshops

A. Each standard adopted by the Council is intended to be clear and readily understandable; if lack of clarity or a susceptibility to misinterpretation is demonstrated, the Council attempts to modify the standard so as to eliminate such flaws. Experience has shown, however, that instruction and interpretation concerning the meaning of the standards is sometimes needed. Occasionally, during the Summation Conference of an on-site survey, the staff of an agency that has been attempting to implement the standards according to its interpretation of them has learned for the first time that its understanding of certain standards was faulty or incomplete.

B. Recognizing its obligation to educate users of the standards in their meaning and application, the Council offers accreditation workshops designed to help service providers and consumer representatives and advocates understand and use the standards and accreditation process to improve services for developmentally disabled individuals. A one-day workshop provides an introduction to the standards and the accreditation process for persons who have little or no knowledge concerning them. A two-day workshop provides an in-depth consideration of the standards for persons who have had some experience in implementing them. However, while an attempt is made to adjust the focus and content of each two-day workshop to the needs and interests of its participants, such a workshop cannot possibly address all the specific problems that a particular agency may encounter in its efforts to interpret and implement standards. Consequently, some agencies have continued to feel a need for interpretations that are specific to their particular situations.

C. Accordingly, the Council also offers on-site workshops, which are held at an agency and are specifically designed to assess whether the agency's staff possesses accurate understanding of the standards, as demonstrated by their efforts to implement them. The on-site workshop is intended for persons who are actively implementing the standards in the settings in which they work, and is addressed to the specific questions that an agency may have in interpreting and implementing standards in its particular setting. On-site workshops are conducted in accordance with the following policies and procedures:

1. The sole and express purpose of an on-site workshop is to assess whether an agency's staff possesses accurate understanding of standards selected by it, as demonstrated by their attempts to implement them. Although on-site workshops are conducted by the Council's surveyors, compliance with standards indicated by the assessments made during a workshop will not be used by the Council in any manner for making any subsequent accreditation decision concerning the agency at which the workshop is held.
2. During an on-site workshop the surveyor will assess compliance with standards in exactly the same manner as during an accreditation survey, except that the agency, rather than the surveyor, will (a) select the standards with which compliance is to be assessed, and (b) select the examples of compliance to be presented for the surveyor's assessment. The surveyor's assessments will be determined by applying the usual criteria of compliance, and will be recorded on the surveyor's regular checklist, which will provide a record of the standards addressed, evidence examined, and assessments determined during the workshop. At the option of the agency, the surveyor will report his or her assessments during his or her examination of the submitted evidence of compliance, or at a final summary conference with the agency's staff, or at both times. Although the background knowledge provided by a two-day workshop is presupposed, the surveyor will also answer questions concerning survey and accreditation procedures. The surveyor will not prepare a report of the workshop (other than the surveyor's checklist), nor will the agency be provided with any written report of the surveyor's assessments.

3. As during an accreditation survey, the surveyor's oral report and comments will be limited to indicating the reasons for concluding that compliance with a standard is deficient, and, where possible, the action that should be taken to correct the deficiency. In suggesting such action, the surveyor may utilize examples of compliance found within the agency itself, as well as examples or alternative methods of compliance that have been observed elsewhere. Where there are alternative methods of achieving compliance with a standard, the surveyor will not recommend any particular method. The surveyor will not assess the feasibility for the agency of any method of achieving compliance with a standard or the feasibility of the agency's attainment of accreditation. (For example, if a deficiency in compliance is related to insufficiently systematic methods of assessing the individual's developmental needs or adaptive behaviors, the surveyor may indicate several scales for this purpose that are in common use, but the surveyor will not recommend use of a particular scale. Again, if deficiencies in service are observed to be related to insufficient available staff time, the surveyor may note that more time might be made available by reallocating staff duties, redeploying existing staff, employing additional staff, or utilizing extramural resources. The surveyor, however, will not recommend specific actions to be taken.)
4. An agency desiring an on-site workshop must submit an application for such a workshop, accompanied by a nonrefundable deposit, which will be in the same amount as the deposit required with an Application for Survey (exclusive of the amount to cover self-survey materials). The application will indicate the standards with which the agency desires its compliance to be assessed. Before submitting such application, the staff of the agency should have familiarized themselves with the indicated standards and have attempted to implement them in the instances that will be presented to the surveyor for assessment of compliance. The charge for an on-site workshop will be the same as for an on-site survey. The agency will determine the number of days that it desires the surveyor to be present, using the following guidelines:
   a) One hour of the surveyor's time must be allocated to assessing compliance with applicable standards in each living unit for which the agency desires assessment.
   b) Three hours of the surveyor's time must be allocated to conduct a program audit for assessing compliance with standards applicable to evaluation, individual program planning, and program implementation for each individual whom the agency desires to present for assessment as an example of compliance with applicable standards.
   c) One hour of the surveyor's time must be allocated to assessing compliance with applicable standards in each program or service area that the agency desires to have assessed.
   d) A program audit must be conducted for at least one individual enrolled in each living unit and each program or service area that the agency desires to have assessed. This requirement will be waived where only the physical environment aspects, as distinguished from the programmatic aspects, of a living unit or program or service area are to be assessed.
   e) At least one-half day (four hours) must be allocated for a summary conference when such is desired.
   f) One day of an on-site workshop must be requested for each eight hours, or fraction thereof, that is to be allocated to the above activities.

Appendix C

Organizations

I. Member Organizations of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons

The year in which each organization became a member of the Accreditation Council is in parentheses following the name of the organization. The Council for Exceptional Children was also a member of the Accreditation Council from 1969 to 1972. Prior to becoming members of the Accreditation Council, the American Academy of Pediatrics, American Nurses' Association, American Psychological Association, Epilepsy Foundation of America, National Association of Private Residential Facilities for the Mentally Retarded, and National Association of Social Workers were represented on Review Committees for the *Standards for Residential Facilities;* and the Epilepsy Foundation of America, National Association of Social Workers, and National Society for Autistic Children were represented in reviewing the draft *Standards for Community Agencies* and the draft *Standards for Agencies Serving Developmentally Disabled Individuals.*

American Academy of Pediatrics (1973)
1801 Hinman Avenue, Evanston, Illinois 60204

American Association on Mental Deficiency (1969)
5101 Wisconsin Avenue, N.W., Washington, D.C. 20016

American Nurses' Association (1973)
2420 Pershing Road, Kansas City, Missouri 64108

American Psychiatric Association (1969)
1700 18th Street, N.W., Washington, D.C. 20009

American Psychological Association (1973)
1200 17th Street, N.W., Washington, D.C. 20036

Epilepsy Foundation of America (1978)
1828 L Street, N.W., Washington, D.C. 20036

National Association for Retarded Citizens (1969)
2709 Avenue "E" East, Arlington, Texas 76010

National Association of Private Residential Facilities
for the Mentally Retarded (1973)
1906 Association Drive, Reston, Virginia 22091

National Association of Social Workers (1978)
1425 H Street, N.W., Washington, D.C. 20005

National Society for Autistic Children (1978)
169 Tampa Avenue, Albany, N.Y. 12208

United Cerebral Palsy Associations (1969)
66 East 34th Street, New York, N.Y. 10016

II. Other national organizations represented in the development of the Standards

The following national organizations, in addition to Member Organizations of the Accreditation Council, were represented in the development of the *Standards* as indicated by the footnotes. Listing of an organization does not imply that it has endorsed the *Standards.*

Academy of Dentistry for the Handicapped, National Foundation of Dentistry for the Handicapped[1,5,6]
1121 Broadway, Boulder, Colorado 80302

American Academy for Cerebral Palsy[1]
University Hospital School, Iowa City, Iowa 52240

American Alliance for Health, Physical Education, and Recreation[1,3,5,6]
1201 16th Street, N.W., Washington, D.C. 20036

American College of Hospital Administrators[1,4]
840 North Lake Shore Drive, Chicago, Illinois 60611

American Dental Hygienists' Association[1,4,5]
211 East Chicago Avenue, Chicago, Illinois 60611

American Dietetics Association[1,4,5]
620 North Michigan Avenue, Chicago, Illinois 60611

American Hospital Association, Psychiatric Services Section[5]
840 North Lake Shore Drive, Chicago, Illinois 60611

American Institute of Architects[1,4]
1735 New York Avenue, N.W., Washington, D.C. 20006

American Library Association[1,5]
50 East Huron Street, Chicago, Illinois 60611

American Medical Record Association[1,5]
875 North Michigan Avenue, Chicago, Illinois 60611

American Occupational Therapy Association[1,5,6]
6000 Executive Boulevard, Rockville, Maryland 20852

American Pharmaceutical Association[1,4,5]
2215 Constitution Avenue, N.W., Washington, D.C. 20037

American Physical Therapy Association[1,4,5,6]
1156 15th Street, N.W., Washington, D.C. 20005

American Professional Workers in United Cerebral Palsy[5]
66 East 34th Street, New York, N.Y. 10016

American Public Health Association[3,5]
1015 18th Street, N.W., Washington, D.C. 20036

American Society for Geriatric Dentistry[1]
861 South State Street, Lincoln, Illinois 62656

American Society for Hospital Food Service Administrators[1,4]
840 North Lake Shore Drive, Chicago, Illinois 60611

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[1] Represented on Review Committee for *Standards for Residential Facilities*

[2] Member of the Accreditation Council during development of *Standards for Residential Facilities*

[3] Represented on Technical Advisory Committee for *Standards for Community Agencies*

[4] Represented in review of draft *Standards for Community Agencies*

[5] Represented on committee for review of draft *Standards for Agencies Serving Developmentally Disabled Individuals*

Submitted written comment on draft *Standards for Agencies Serving Developmentally Disabled Individuals*

American Society of Dentistry for Children[1][4]
211 East Chicago Avenue, Chicago, Illinois 60611

American Society of Hospital Pharmacists[1][4][5]
4630 Montgomery Avenue, Washington, D.C. 20014

American Speech and Hearing Association[1][4][5]
9030 Old Georgetown Road, Washington, D.C. 20014

Association for Administration of Volunteer Services[1][4][5]
18 South Michigan Avenue, Chicago, Illinois 60603

Association for Clinical Pastoral Education[1][4]
475 Riverside Drive, New York, N.Y. 10027

Association of Mental Health Administrators[1][4][5]
2901 Lafayette, Lansing, Michigan 48906

Association of Mental Health Chaplains[1][5]
1700 18th Street, N.W., Washington, D.C. 20009

Association of University Affiliated Facilities[3][5]
2600 Virginia Avenue, N.W., Washington, D.C. 20037

Center for a Voluntary Society[1]
1507 M Street, N.W., Washington, D.C. 20005

Child Welfare League of America[1][3][5]
44 East 23rd Street, New York, N.Y. 10010

Commission for the Control of Epilepsy and its Consequences[5]
7550 Wisconsin Avenue, Bethesda, Maryland 20014

Conference of Executives of American Schools for the Deaf[1]
5034 Washington Avenue, N.W., Washington, D.C. 20016

Council for Exceptional Children[2][3][5]
1411 Jefferson Davis Highway, Arlington, Virginia 22202

Family Service Association of America[1]
44 East 23rd Street, New York, N.Y. 10010

Mental Retardation Association of America[5]
211 East 3rd South, Salt Lake City, Utah 84111

National Association for Music Therapy[1][6]
P.O. Box 610, Lawrence, Kansas 66044

National Association of Catholic Chaplains[1]
1312 Massachusetts Avenue, N.W., Washington, D.C. 20005

National Association of Coordinators of State Programs
for the Mentally Retarded[1][3][5]
2001 Jefferson Davis Highway, Arlington, Virginia 22202

National Association of Epilepsy Executives[5]
733 15th Street, N.W., Washington, D.C. 20005

National Association of Superintendents of Public Residential Facilities
for the Mentally Retarded[1][3][5]

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[1] Represented on Review Committee for *Standards for Residential Facilities*

[2] Member of the Accreditation Council during development of *Standards for Residential Facilities*

[3] Represented on Technical Advisory Committee for *Standards for Community Agencies*

[4] Represented in review of draft *Standards for Community Agencies*

[5] Represented on committee for review of draft *Standards for Agencies Serving Developmentally Disabled Individuals*

[6] Submitted written comment on draft *Standards for Agencies Serving Developmentally Disabled Individuals*

National Conference of Executives of Associations for Retarded Citizens[5]
2709 Avenue "E" East, Arlington, Texas 76010

National Conference on Developmental Disabilities[5]

National Conference of Churches of Christ in the U.S.A.[1]
475 Riverside Drive, New York, N.Y. 10027

National League for Nursing[1]
10 Columbus Circle, New York, N.Y. 10019

National Rehabilitation Association[1] [5]
1522 K Street, N.W., Washington, D.C. 20005

National Recreation and Park Association[4]
1201 Sixteenth Street, N.W., Washington, D.C. 20036

National Therapeutic Recreation Society[1] [4] [5] [6]
1201 Sixteenth Street, N.W., Washington, D.C. 20036

President's Committee on Mental Retardation[1] [3] [5]
Washington, D.C. 20201

Religious Certification Agency for Retardation[1]
c/o The Devereaux Foundation, Devon, Pennsylvania 19333

Society for the Advancement of Management[1]
1472 Broadway, New York, N.Y. 10036

III. Other organizations referred to in the Standards

The following organizations promulgate standards, codes, or regulations referred to in the *Standards.*

American College of Chest Physicians
112 East Chestnut Street, Chicago, Illinois 60611

American Electroencephalographic Society
38238 Glenn Avenue, Willoughby, Ohio 44094

American National Standards Institute (A.N.S.I. Standards)
1430 Broadway, New York, N.Y. 10018

Food and Nutrition Board, National Research Council
2101 Constitution Avenue, N.W., Washington, D.C. 20418

National Fire Protection Association
60 Batterymarch Street, Boston, Massachusetts 02110

National Society of Fund Raisers
130 East 40th Street, New York, N.Y. 10016

Occupational Safety and Health Administration
U.S. Department of Labor, Washington, D.C. 20210

U.S. Public Health Service
5600 Fishers Lane, Rockville, Maryland 20852

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[1] Represented on Review Committee for *Standards for Residential Facilities*

[2] Member of the Accreditation Council during development of *Standards for Residential Facilities*

[3] Represented on Technical Advisory Committee for *Standards for Community Agencies*

[4] Represented in review of draft *Standards for Community Agencies*

[5] Represented on committee for review of draft *Standards for Agencies Serving Developmentally Disabled Individuals*

[6] Submitted written comment on draft *Standards for Agencies Serving Developmentally Disabled Individuals*

Appendix D

Councillors of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons

The name of the appointing Council Member Organization and the term of office are in parentheses following the name of the councillor. For identification purposes only, agency affiliation (if any) during term of office is also indicated.

Howard V. Bair, M.D. (American Psychiatric Association, 1969-73), Parsons State Hospital and Training Center, Parsons, Kansas

Allan Barclay, Ph.D. (American Psychological Association, 1973-76), St. Louis University, St. Louis, Missouri

Harold A. Benson, Jr. (Epilepsy Foundation of America, 1978-), Epilepsy Foundation of America, Washington, D.C.

Norman R. Bernstein, M.D. (American Psychiatric Association, 1977-), University of Illinois, Chicago, Illinois

Walter J. Cegelka, Ed.D. (National Association for Retarded Citizens, 1975-76), University of Missouri, St. Louis, Missouri

James P. Chapman (National Association for Retarded Citizens, 1977-), Columbia, Maryland

James D. Clements, M.D. (American Association on Mental Deficiency, 1975-), Georgia Retardation Center, Atlanta, Georgia

Gerald R. Clark, M.D. (American Psychiatric Association, 1974-), Elwyn Institute, Elwyn, Pennsylvania

James G. Foshee, Ph.D. (American Psychological Association, 1977-), Tennessee Department of Mental Health, Nashville, Tennessee

Albert C. Fremont, M.D. (American Academy of Pediatrics, 1978-), Santa Clara Valley Medical Center, San Jose, California

Jack Hammond, M.D., deceased, (American Psychiatric Association, 1969-1973), Rome State School, Rome, New York

Dennis Hansen (National Society for Autistic Children, 1978-), New York, N.Y.

Elsie D. Helsel, Ph.D. (United Cerebral Palsy Association, 1969-1974), United Cerebral Palsy Association, Washington, D.C.

Maryanne Keenan (National Association of Social Workers, 1978-), National Association of Social Workers, Washington, D.C.

Eleanor Kephart (National Association for Retarded Citizens, 1969-74), Meadville, Pennsylvania

Lewis B. Klebanoff, Ph.D. (American Psychological Association, 1973-77), Massachusetts Department of Mental Health, Boston, Massachusetts

Paul Krentel (National Association of Private Residential Facilities for the Mentally Retarded, 1977-), Melmark Home, Berwyn, Pennsylvania

Joseph W. Kunz, Ed.D. (Council for Exceptional Children, 1973), National Center for Law and the Handicapped, South Bend, Indiana

Dorothy Leber (United Cerebral Palsy Associations, 1975-), Peoria, Illinois

Joseph S. Lerner, Ed.D. (Council for Exceptional Children, 1969-1972), San Francisco State College, San Francisco, California

Horace Mann, Ph.D. (American Association on Mental Deficiency, 1977-), State University College at Buffalo, Buffalo, N.Y.

Richard L. Masland, M.D. (Epilepsy Foundation of America, 1978-), Columbia University, New York, N.Y.

Brian McCann, Ph.D. (National Association for Retarded Citizens, 1973-), National Association for Retarded Citizens, Arlington, Texas

Alan A. McClelland (National Society for Autistic Children, 1978-), Webster Groves, Missouri

Floyd E. McDowell, Ed.D. (Council for Exceptional Children, 1969), Metropolitan New York Regional Training Center, New York, N.Y.

John McIvor (National Association of Private Residential Facilities for the Mentally Retarded, 1973-76), Cedars Development Foundation, Ross, California

Jean L. McMahon, M.D. (American Academy of Pediatrics, 1975-), Children's Hospital, Denver, Colorado

Allan R. Menefee (American Association on Mental Deficiency, 1969-73), President's Committee on Mental Retardation, Washington, D.C.

Sherwood A. Messner (United Cerebral Palsy Associations, 1969-73), United Cerebral Palsy Associations, New York, N.Y.

Sally M. O'Neil, Ph.D. (American Nurses' Association, 1973-76), University of Washington, Seattle, Washington

E. Gene Patterson (National Association for Retarded Citizens, 1969-73), National Association for Retarded Citizens, Arlington, Texas

Nancy J. Patterson, R.N. (American Nurses' Association, 1977-), Partlow Human Rights Committee, Partlow, Alabama

Paul H. Pearson, M.D. (American Academy of Pediatrics, 1973-74), University of Nebraska Medical Center, Omaha, Nebraska

Terry Perl (National Association of Private Residential Facilities for the Mentally Retarded, 1975-), The Chimes, Baltimore, Maryland

David Rosen (American Association on Mental Deficiency, 1974-75), Macomb-Oakland Regional Center, Fraser, Michigan

Harry Schonfeld (National Association of Social Workers, 1978-), California Department of Health, Pomona, California

Theodore D. Scurletis, M.D. (American Academy of Pediatrics, 1973-77), Iowa Board of Health, Des Moines, Iowa

Albert J. Shafter, Ph.D. (American Association on Mental Deficiency, 1971-74, 1976-77), A. L. Bowen Children's Center, Harrisburg, Illinois

Andrew L. Shotick, Ph.D. (Council for Exceptional Children, 1970-72), Georgia Retardation Center, Athens, Georgia

William P. Sloan, Ph.D. (American Association on Mental Deficiency, 1969-70), Illinois Department of Mental Health, Springfield, Illinois

Leon Sternfeld, M.D. (United Cerebral Palsy Associations, 1973-), United Cerebral Palsy Associations, New York, N.Y.

George Tarjan, M.D. (American Psychiatric Association, 1973-76), U.C.L.A. Neuropsychiatric Institute, Los Angeles, California

Natalie Twardzicki, R.N. (American Nurses' Association, 1973-), Wrentham State School, Wrentham, Massachuetts

James O. Vammen (National Association of Private Residential Facilities for the Mentally Retarded, 1973-74), Office of Mental Retardation, Pennsylvania Department of Public Service, Harrisburg, Pennsylvania

Sue A. Warren, Ph.D. (American Psychological Association, 1978-), Boston University, Boston, Massachusetts

Glossary

Insofar as possible, technical or specialized terms employed in the *Standards* are used in accordance with the definitions given in *Webster's New Collegiate Dictionary* (Springfield, Mass.: G. & C. Merriam, 1975), or are defined in the context in which they occur. Terms defined in this Glossary include: (1) terms whose dictionary definition is inadequate or ambiguous for the purposes of the *Standards*; (2) terms that require fuller definition, exemplification, or reference than it is feasible to provide in the body of the *Standards;* and (3) terms that are used in several standards but are not defined in all of them, and that are defined here for convenience of reference. Glossary definitions give the meaning of such terms as they are used in these *Standards*. Terms may be added to and deleted from future editions of the Glossary on the basis of accumulated experience with the *Standards*.

Definitions given in introductions to the Sections of the *Standards* are not always repeated here.

adaptive behavior In general, the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age and cultural group. Meeting these standards requires specific adaptive behaviors, such as those pertaining to self-help and independent-living skills.

advocate A person who represents the rights and interests of an individual as though they were the person's own, in order to realize the rights to which the individual is entitled, obtain needed services, and remove barriers to meeting the individual's needs.

agency An organization that provides services to developmentally disabled individuals or their families. The agency need not limit its services to developmentally disabled individuals; it may serve such individuals as part of the general public to which it offers services.

appropriate Term used to indicate that a requirement is to be applied according to the needs of a particular individual or situation. When used to qualify a requirement concerning participation or involvement of the individual, the terms "as appropriate" or "when appropriate" are applicable only when there is documented evidence that the individual is completely incapable of comprehending any aspect of the proceding, instruction, or commentary. When used to qualify a requirement concerning participation or involvement of the individual's family or advocate, the terms "as appropriate" or "when appropriate" refer particularly to the fact that such participation or involvement is inappropriate when it is contrary to the wishes of an adult individual who has not been legally determined to be incompetent.

behavior modification A technique that is based on reliable data concerning the functional relationship between an environmental event and a behavioral event, and that is designed to alter the frequency of the behavioral event by manipulating the environmental event that is related to it.

behavior modifying drugs and drugs used for behavior management Drugs that are prescribed or administered for the purpose of modifying behavior. Included are the major and minor tranquilizers (neuroleptic and anxiolytic drugs) and antidepressants (imipramine-type drugs, monoamine oxidase inhibitors, and psychomotor stimulants). Excluded are drugs that may have behavior-modifying effects but that are not prescribed or administered for that purpose, such as anticonvulsants.

chief executive officer The individual appointed by the governing body of an agency to act in its behalf in the overall management of the agency. Job titles may include, but are not limited to, superintendent, director, and administrator.

community A population having a common interest or interdependency in the delivery of services.

corporal punishment The application of a painful stimulus to the body in an attempt to terminate behavior or as a penalty for behavior, other than when applied as part of a systematic behavior modification program that involves the use of noxious or aversive stimuli and meets all applicable standards.

culturally normative That which is normal, typical, or usual for a given culture, such as the attitudes, performances, or behaviors ordinarily displayed by or expected of most individuals within a given region, community, or ethnic group.

dead time Unscheduled or unstructured time during which no alternative activities are effectively available to the individual, so that there is nothing for the individual to do except wait for the next activity. Dead time is distinguished from free or leisure time, which is unstructured time during which two or more alternative activities are available for the individual's choice, with appropriate equipment or materials, if needed.

developmental disabilities Disabilities that become evident in childhood, that are expected to continue indefinitely, that constitute a substantial handicap to the affected individual, and that are attributable to mental retardation, cerebral palsy, epilepsy, autism, or another neurological condition closely related to, or requiring treatment similar to that required by, mental retardation.

direct supervision Means that work is performed under the guidance and direction of a supervisor who is responsible for the work, who plans work and methods, who is available on short notice to answer questions and deal with problems that are not strictly routine, who regularly reviews the work performed, and who is accountable for the results.

drugs used for behavior management See behavior modifying drugs.

employees All persons who are paid for work performed at the agency, whether or not they are paid by the agency itself.

family Parents, brothers, sisters, foster parents, guardians, surrogates, and others who perform the roles and functions of natural family members in the lives of individuals.

generic services Services offered or available to the general public, as distinguished from specialized services that are intended only for developmentally disabled individuals.

goal An expected result or condition that involves a relatively long period of time to achieve, that is specified in behavioral terms in a statement of relatively broad scope, and that provides guidance in establishing specific, short-term objectives directed toward its attainment.

governing board The group of individuals that constitutes the governing body of an agency. A governing board may be called a board of trustees, board of directors, or board of governors. It represents one form of a governing body.

guardian An individual who has legal control and management of the person, or of the property or estate, or of both the person and property, of a ward.

guardian of the person A guardian appointed to assure that the ward receives proper care and protective supervision in keeping with his or her needs.

guardian of the property A guardian appointed to assure that the financial affairs of the ward are handled in his or her best interests.

legal guardian A guardian appointed by a court.

natural guardian A parent lawfully in control of the person of his or her minor child; natural guardianship terminates when the child attains majority.

plenary guardian A guardian who has full guardianship of both the person and property of the ward.

public guardian A public official empowered to accept court appointment as a legal guardian.

successor guardian A legal guardian appointed by a court when an already functioning guardian dies, is removed by the court, or resigns.

standby guardian A guardian nominated by the parents during their lives, and recognized by the court, to act in their place upon their incapacitation or death.

testamentary guardian A legal guardian nominated in the will of a parent of a minor child. A testamentary guardian may be of the person, of the estate, or of both the person and the estate.

temporary guardian A legal guardian appointed by a court upon notice that a person is in immediate need of guardianship. A temporary guardian may be guardian of the person, of the estate, or of both the person and the estate.

guardian ad litem An individual appointed to represent a ward in a particular legal proceeding, without control over either the ward's person or estate.

habilitation The process by which the staff of an agency assists an individual to acquire and maintain those life skills that enable the individual to cope more effectively with the demands of his or her own person and environment and to raise the level of his or her physical, mental, and social functioning. Habilitation includes, but is not limited to, programs of formal, structured education and treatment.

indigenous leadership Leadership that is derived from within the community or group in which it is exercised, as, for example, leadership that is derived from the parents or friends of developmentally disabled individuals or from such individuals themselves, as contrasted with leadership that is derived from without.

individual Term used in this document to refer to a person who receives, or who may need to receive, services from an agency.

interdisciplinary team A group of persons that is drawn from or represents those professions, disciplines, or service areas that are relevant to identifying an individual's needs and designing a program to meet them, and that is responsible for evaluating the individual's needs, developing an individual program plan to meet them, periodically reviewing the individual's response to the plan, and revising the plan accordingly. A complete team includes the individual being served, unless clearly unable to participate; the individual's family, unless their participation has been determined to be inappropriate; those persons who work most directly with the individual in each of the professions, disciplines, or service areas that provide service to the individual, including direct-care or direct-contact staff; and any other persons whose participation is relevant to identifying the needs of the individual and devising ways to meet them. The group functions in an interdisciplinary manner as described in Section 1.1 of the *Standards.*

least restrictive alternative That intervention into the life of a developmentally disabled individual that is the least intrusive into, and least disruptive of, the individual's life, and that represents the least departure from normal patterns of living that can be effective in meeting the individual's developmental needs.

least restrictive environment That environment that represents the least departure from normal patterns of living that can be effective in meeting the individual's needs.

legal incompetence The legal determination that an individual is unable to exercise his or her full civil and legal rights, and that a guardian is required.

living unit A residential unit that includes sleeping, dining, and activity areas.

mapping Moving from one place to another within the environment in a safe, effective, and comfortable manner by using such cues as size, shape, odor, and landmarks.

mobile nonambulatory Unable to walk without assistance, but able to move from place to place with the use of such devices as walkers, crutches, wheelchairs, and wheeled platforms.

nonambulatory Unable to walk independently without assistance.

normalization The principle of helping developmentally disabled individuals to obtain an existence as close to the normal as possible, by making available to them patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream of society. Specifically, the use of means that are as culturally normative as possible to elicit and maintain behaviors and characteristics that are as culturally normative as possible, taking into account local and subcultural values and mores.

objective An expected result or condition that involves a relatively short period of time to achieve, that is specified in behavioral terms, and that is related to the achievement of a goal.

orientation Awareness of one's position in relation to the environment and significant objects within the environment.

program A structured set of activities to achieve specific objectives, relative to the developmental needs of the individuals served by an agency. An agency may provide more than one program.

program group A group of not more than eight residents who have similar needs and individual programs, and for whom a specific staff member is responsible for providing or coordinating an organized program of care, training, and recreation, in accordance with the individual program plans of the group members.

restraint	Any physical or mechanical device used to restrict the movement of an individual or the movement or normal function of a portion of the individual's body, excluding only devices used to provide support for the achievement of functional body position or proper balance, and devices used for specific medical and surgical (as distinguished from behavioral) treatment.
service delivery system	The network of service components, specialized and generic, that is directed toward meeting the general and extraordinary needs of developmentally disabled individuals in the population served.
surrogate	A person who functions in place of an individual's parents or family.
time out	Time out from positive reinforcement: a behavior modification procedure in which, contingent upon the emission of undesired behavior, the individual is removed from the situation that affords positive reinforcement.
time-out device	An apparatus, such as a restraint or time-out room, that is employed to enforce timing-out of an individual.
trustee	A person appointed or required by law to execute a trust; one in whom an estate, interest, or power is vested, under an expressed or implied agreement to administer or exercise it for the benefit, or to the use of, another.
unit record	The main record that contains all pertinent information concerning the services provided to an individual by an agency, and that is located in one place within the agency's record system.